

# **UNDERSTANDING EPILEPSY WITHIN HISTORICALLY BLACK SCHOOLS IN THE WESTERN CAPE**

by

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**Thesis in partial fulfilment of the requirements**

**for the degree**

**Master of Education in Educational Psychology**

**(M Ed Psych)**

at

**Stellenbosch University**

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**March 2010**

## **Declaration**

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

15 February 2010

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## ABSTRACT

This study was conducted within historically black schools in the Western Cape. According to ([HSRP@historicsschools.org.za](mailto:HSRP@historicsschools.org.za)) historically Black schools are identified as schools which under the apartheid government were racially segregated schools, situated mainly in residential areas populated by people classified as black, for the exclusive use of people in this racial classification category. The purpose of this study was to explore educators', parents' and learner understands of epilepsy. This study uses an interpretive research framework to obtain in-depth data on educators', parents' and learner's knowledge of epilepsy, reactions of educators towards learners with epilepsy, the effect of epilepsy on learning and the inclusion of learners with epilepsy in a regular class. The thematic content analysis was the method of analysis. Participants' experiences with regard to epilepsy were reconstructed according to themes. Recurring themes were linked with the literature.

This study found that educators, parents and learners had little idea what epilepsy entails and their beliefs were often moulded by inaccurate information. Educators have received little or no training to provide meaningful support for learners with epilepsy. Despite policy changes the needs of learners with epilepsy are not met in the classroom. Educators and parents insist that they need information, skills and clear guidelines regarding epilepsy. Research indicates that educators find it difficult to cope with the demands of these learners, and often experience frustration and failure. It could benefit the schools if a supporting programme is developed to provide practical and comprehensive guidelines to assist educators to support learners with epilepsy.

# OPSOMMING

Hierdie navorsing is in histories swart skole in die Weskaap onderneem. HSRP@historicschools.org.za beskryf 'histories swart skole' as skole wat tydens die apartheid-regime op grond van ras gesegregeer was, hoofsaaklik binne residensiële areas wat bewoon is deur mense wat as swart geklassifiseer is, vir die eksklusiewe gebruik van mense van hierdie rasseklassifikasie. Die doel van hierdie navorsing is om opvoeders, ouers en leerders se begrip van epilepsie te ondersoek. 'n Interpretatiewe navorsingsraamwerk is gebruik om in-diepte gegewens rakende opvoeders, ouers en leerders se kennis van epilepsie, opvoeders se reaksie teenoor leerders met epilepsie, die uitwerking van epilepsie op leer, en die insluiting van leerders met epilepsie in gewone klasse, in te win. Die tematiese inhoudsanalise is gebruik as ondersoekmetode. Deelnemers aan die studie se ervarings van epilepsie is volgens temas gerekonstrueer. Herhalende temas is met die literatuur oor die onderwerp verbind.

Die navorsing het bevind dat opvoeders, ouers en leerders weinig benut het van wat epilepsie is, en dat hulle begrip daarvan dikwels deur onakkurate inligting gevorm is. Opvoeders ontvang weinig of geen opleiding om betekenisvolle ondersteuning aan leerders met epilepsie te gee. Ten spyte van beleidsveranderinge word daar nie aan die behoeftes van leerders met epilepsie in die klaskamer voldoen nie. Opvoeders en ouers hou vol dat hulle inligting, vaardighede en duidelike riglyne rakende epilepsie nodig het. Navorsing wys dat opvoeders dit moeilik vind om raad te weet met hierdie leerders se behoeftes, en dat hulle dikwels frustrasie ervaar en voel dat hulle misluk het in hulle pogings. Die ontwikkeling van 'n ondersteuningsprogram, wat praktiese en omvattende riglyne daarstel om opvoeders met die behoeftes van leerders met epilepsie te assisteer, kan tot die voordeel van skole wees.

## DEDICATION

*I would like to dedicate this mini thesis to my late grandmother Marose Vuyiswa Rose Nonyalela, mother 'Lhina' Maureen Nontutuzelo Nonyalela, brother 'Nkala' Vusumzi Nonyalela and my youngest sister 'Yola' Nokuyola Nonyalela. Life without all of you has not been easy – it is never easy losing people you love. But, with God, I know you are all safe. Please remember that I will always love you and that I cherished the years the Almighty allowed me to spend with you. I wish all of you were alive to witness and celebrate this accomplishment with me.*

## ACKNOWLEDGEMENTS

- My husband, Mike Lupondo, and my beautiful children Athi and Azande - thank you very much for your support and understanding. I know all of this work has taken my time away from you and sometimes I didn't pay enough attention to all of you. But you all understand and allowed me to finish this thesis without any complaints. Always know that I love you and I am blessed to have a beautiful family like you.
- To my two lovely sisters Themba, Yoyo and, brother Sandile - without you guys I'm nothing. Thank you for always encouraging me during my difficult times in life and ensuring me that I must hang on because I will do it. Well, guess what? I have done it.
- To all my friends especially Balie – sisi, you know the role you have played to my family. I don't need to mention it Enkosini Bethuna ngento yonke. I am so grateful to my colleagues, for being listening ears in times of need and for that question: "Yolanda, how far are you now with your thesis?" How you encouraged me, you'll never know, Nangomso.
- To my supervisor Lynette Collair - thanks for believing in me through your words of wisdom and encouragement.
- To God, I thank YOU for making me the person I am today and for those around me always.

# TABLE OF CONTENTS

|                                |            |
|--------------------------------|------------|
| <i>Declaration</i> .....       | <i>i</i>   |
| <i>Abstract</i> .....          | <i>ii</i>  |
| <i>Opsomming</i> .....         | <i>iii</i> |
| <i>Declaration</i> .....       | <i>iv</i>  |
| <i>Acknowledgements</i> .....  | <i>v</i>   |
| <i>Table of contents</i> ..... | <i>vi</i>  |

## CHAPTER 1

### CONTEXTUALISING THE STUDY ..... 1

|  |   |
|--|---|
| 1.1 INTRODUCTION .....                     | 1 |
| 1.2 BACKGROUND TO THE STUDY.....           | 1 |
| 1.3 PERSONAL MOTIVATION FOR THE STUDY..... | 2 |
| 1.4 PROBLEM STATEMENT .....                | 2 |
| 1.5 RESEARCH AIMS AND QUESTIONS.....       | 5 |
| 1.6 RESEARCH DESIGN .....                  | 5 |
| 1.7 DEFINITION OF KEY TERMS.....           | 7 |
| 1.7.1 Epilepsy.....                        | 7 |
| 1.7.2 Historically Black Schools.....      | 7 |
| 1.7.3 Indigenous Knowledge .....           | 7 |
| 1.7.4 Inclusive education .....            | 8 |
| 1.8 OUTLINE OF THESIS.....                 | 8 |

## CHAPTER 2

### LITERATURE REVIEW ..... 9

|  |    |
|--|----|
| 2.1 INTRODUCTION .....   | 9  |
| 2.2 AN INTRODUCTION TO EPILEPSY .....                          | 9  |
| 2.3 WHAT IS EPILEPSY? .....                                    | 9  |
| 2.3.1 Prevalence .....   | 10 |
| 2.3.2 Causes of epilepsy .....                                 | 10 |
| 2.3.3 The different and characteristics forms of epilepsy..... | 11 |
| 2.4 DIAGNOSIS OF EPILEPSY .....                                | 14 |
| 2.4.1 Medical history.....                                     | 14 |
| 2.4.2 Blood test and brain scans.....                          | 15 |

|       |  |    |
|-------|--|----|
| 2.4.3 | The Electroencephalogram (EEG).....                                    | 15 |
| 2.5   | EDUCATIONAL PROVISIONAL FOR LEARNERS WITH EPILEPSY .....               | 15 |
| 2.5.1 | Education implications of epilepsy.....                                | 15 |
| 2.6   | INDIGENOUS KNOWLEDGE.....  | 18 |
| 2.6.1 | What is Indigenous Knowledge? .....                                    | 18 |
| 2.6.2 | Why is Indigenous Knowledge important?.....                            | 18 |
| 2.6.3 | Indigenous knowledge: International context .....                      | 19 |
| 2.6.4 | Indigenous knowledge in South Africa .....                             | 19 |
| 2.7   | AFRICA'S CULTURAL VIEW ON EPILEPSY .....                               | 21 |
| 2.7.1 | Epilepsy in Africa.....  | 22 |
| 2.7.2 | Traditional healer's treatment of disease and illness (epilepsy) ..... | 29 |
| 2.8   | AN INTEGRATED APPROACH .....   | 30 |
| 2.9   | WHAT IS INCLUSION?.....  | 31 |
| 2.9.1 | What is Inclusive Education?.....                                      | 32 |
| 2.9.2 | History of Inclusive Education.....                                    | 32 |
| 2.9.3 | Education in post-Apartheid South Africa.....                          | 33 |
| 2.9.4 | History of education and special education .....                       | 34 |
| 2.9.5 | Inclusive education for learners with epilepsy.....                    | 35 |

### **CHAPTER 3**

#### **RESEARCH METHODOLOGY ..... 42**

|     |                                   |    |
|-----|-----------------------------------|----|
| 3.1 | INTRODUCTION .....                | 42 |
| 3.2 | RESEARCH DESIGN .....             | 42 |
| 3.3 | RESEARCH PARTICIPANTS .....       | 44 |
| 3.4 | DATA COLLECTION METHODOLOGY ..... | 45 |
| 3.5 | DATA ANALYSIS TECHNIQUES .....    | 48 |
| 3.6 | RELIABILITY AND VALIDITY.....     | 49 |
| 3.7 | RESEARCH ETHICS .....             | 50 |
| 3.8 | SUMMARY AND CONCLUSION .....      | 51 |

### **CHAPTER 4**

#### **PRESENTATIONS OF FINDINGS ..... 52**

|     |                    |    |
|-----|--------------------|----|
| 4.1 | INTRODUCTION ..... | 52 |
|-----|--------------------|----|



|       |   |    |
|-------|---|----|
| 4.2   | EDUCATOR, PARENT AND LEARNER UNDERSTANDING OF EPILEPSY<br>WITHIN HISTORICALLY BLACK SCHOOLS IN THE WESTERN CAPE ..... | 52 |
| 4.2.1 | Knowledge about epilepsy .....  | 52 |
| 4.2.2 | Reactions of educators towards learners with epilepsy .....   | 53 |
| 4.2.3 | Effect of epilepsy on learning .....  | 54 |
| 4.2.4 | Inclusion in regular class.....   | 54 |
| 4.2.5 | The need for school guidelines.....   | 55 |
| 4.2.6 | The need for curriculum change.....   | 55 |
| 4.2.7 | Teacher education support .....   | 56 |
| 4.3   | LEARNERS UNDERSTANDING ABOUT EPILEPSY.....  | 57 |
| 4.3.1 | Learner's knowledge about epilepsy.....   | 57 |
| 4.3.2 | Reactions of other learners towards the learners with epilepsy .....  | 57 |
| 4.4   | PARENTS UNDERSTANDING ABOUT EPILEPSY .....  | 58 |
| 4.4.1 | Parents' knowledge about epilepsy .....   | 58 |
| 4.4.2 | Reactions of community towards the learners with epilepsy.....  | 59 |
| 4.4.3 | Medication used for epilepsy .....  | 59 |
| 4.5   | CONCLUSION .....  | 61 |

## **CHAPTER 5**

|       |   |           |
|-------|---|-----------|
|       | <b>DISCUSSIONS AND RECOMMENDATIONS .....</b>              | <b>62</b> |
| 5.1   | INTRODUCTION .....  | 62        |
| 5.2   | DISCUSSIONS OF FINDINGS .....                             | 62        |
| 5.3   | LINKS TO PREVIOUS RESEARCH FINDINGS .....                 | 63        |
| 5.4   | THE NEED FOR TRAINING AND SUPPORT .....                   | 64        |
| 5.5   | THE NEED FOR COMMUNITY INVOLVEMENT .....                  | 64        |
| 5.6   | THE NEED FOR MEDICAL TREATMENT .....                      | 65        |
| 5.7   | RECOMMENDATIONS .....                                     | 65        |
| 5.7.1 | Schools to identify and have some source of support.....  | 66        |
| 5.7.2 | Engage the community .....                                | 66        |
| 5.8   | SUGGESTIONS FOR FURTHER RESEARCH.....                     | 67        |
| 5.9   | LIMITATION OF THIS RESEARCH .....                         | 67        |
| 5.10  | CONCLUSION .....  | 67        |
|       | <b>REFERENCES.....</b>                                    | <b>69</b> |
|       | <b>APPENDIX A: INTERVIEW SCHEDULE FOR EDUCATORS .....</b> | <b>81</b> |
|       | <b>APPENDIX B: INTERVIEW SCHEDULE FOR PARENTS.....</b>    | <b>83</b> |

|                    |  |           |
|--------------------|--|-----------|
| <b>APPENDIX C:</b> | <b>INTERVIEW SCHEDULE FOR LEARNERS.....</b>  | <b>85</b> |
| <b>APPENDIX D:</b> | <b>THE TRANSLATED INTERVIEW: (PARTICIPANTS,<br/>EDUCATOR) EXAMPLE OF CODED TRANSCRIPTS<br/>FOR DATA ANALYSIS .....</b> | <b>87</b> |
| <b>APPENDIX E:</b> | <b>SUMMARY OF FIELD NOTES RELATED TO<br/>INTERVIEW SCHEDULE.....</b>   | <b>90</b> |
| <b>APPENDIX F:</b> | <b>CONSENT FORM FOR EDUCATORS, PARENTS<br/>LEARNERS.....</b>   | <b>92</b> |
| <b>APPENDIX G:</b> | <b>LETTERS OF PERMISSION .....</b>   | <b>96</b> |

# **CHAPTER 1**

## **CONTEXTUALISING THE STUDY**

### **1.1 INTRODUCTION**

This chapter provides information on the background of the study. It also looks at the motivation behind the choice of topic as well as the aim of the research and the research methodology. Finally, it will provide an outline of the rest of this thesis.

### **1.2 BACKGROUND TO THE STUDY**

The main focus of this research is to investigate the level of understanding and knowledge of epilepsy among educators, parents and learners within the context of historically black schools in the Western Cape. There are many myths around the word "epilepsy"; people have varying views and perceptions about it. This research seeks to create an awareness of epilepsy, since it does exist in our schools, and learners who live with it often become victims of discrimination. They can experience learning barriers due to epilepsy and be made to feel inadequate and pressurised.

The aim of this research is to contribute to the understanding of epilepsy so that learners with epilepsy can get the support they need in order to learn successfully. It will investigate how educators, parents and learners within historically Black schools in the Western Cape understand epilepsy. It will discuss the condition in depth and look at why inclusive education is important when dealing with learners with epilepsy. It will examine what the school and the community can and should do in order to accommodate and accept these learners without any discrimination. With reference to the specific context of the study, it is known that many people in the Western Cape, including persons and family members of persons with epilepsy, consult traditional healers for help with epilepsy. This study will therefore also discuss the indigenous knowledges and understanding of the condition in a South African and African context.

### 1.3 PERSONAL MOTIVATION FOR THE STUDY

As an educator in historically Black schools in the Western Cape, I experienced that there are many misconceptions and social discriminations associated with the condition of epilepsy and the people who live with it.

In schools, the word "epilepsy" still carries a stigma as the following experience will demonstrate:

*Once, while teaching, I witnessed a learner having a seizure. I recall that I was terrified and that I felt helpless in that I did not know what to do to help the little girl. When the seizure had passed, she was extremely embarrassed about it and seemed not to remember what had happened. Other learners in the class started to tease her, until, as was the school's procedure, her parents were called in. When her mother was told what had happened to her child, she was convinced that there was nothing wrong with the girl. She believed she had been possessed by an evil spirit and bewitched by her neighbour because people were jealous of her achievements. Interestingly, and to my surprise, some of my colleagues (educators) strongly agreed with the mother. It occurred to me that sometimes people believe what they commonly hear and experience rather than that which is known through careful research. When the parent explained that someone was bewitching her child I questioned whether this belief was particular to this parent or whether it was commonly held by parents and educators in Black communities.*

Personal experiences can have a strong impact and be a forceful source of knowledge. Sometimes what is perceived to be true may actually be due to a slight error or distortion in judgment. It has been acknowledged that there is a wide variety of influences on people's beliefs about illness and treatment, particularly when it comes to culture and religion. Beliefs about health and illness affect people's decisions about their choice of treatment. They can exert positive influences by being supportive and resourceful or negative influences when they translate into discrimination and/or labelling.

### 1.4 PROBLEM STATEMENT

Numerous studies have been conducted on the subject and they reveal that the myths and misconceptions surrounding people with epilepsy continue. Throughout history, misconceptions and prejudice about people with epilepsy have been common. Often people with epilepsy were considered to be possessed by evil spirits or to be insane (Heller, Alberto,

Forney & Schwartzman, 1996:74). A quote from Hippocrates in 'The Sacred Disease' explains that individuals who had epilepsy were burned at the stake like witches and those thought to be possessed (Heller et al., 1996). Even before the 20<sup>th</sup> century they were frequently locked away or jailed because they were considered insane (Temkin, 1971). While these ideas may have changed in many Western contexts, this is not always the case in traditional societies.

Myths and misunderstanding continue to affect learners with epilepsy. A variety of studies confirm that people have culturally different views about what causes epilepsy. A study conducted in 2006 by Ismail, Wright, Rhodes and Small explored how people construct their knowledge. The study was conducted among South Asian communities in the United Kingdom. It explored the influences of spiritual and religious beliefs on the cause of epilepsy and the choice of treatment of epilepsy in people of South Asian origin. It was found that over half the participants attributed their illness to fate and the will of God, or as punishment for sins of a past life. Some participants had experienced prejudice from people who believed that their epilepsy was contagious. A strong network of traditional healers was found providing a parallel system of health care in the United Kingdom and on the Indian subcontinent (Ismail, Wright, Rhodes & Small, 2005). People turned to religious or spiritual treatments in desperation for a cure, often under the influence of their families after the perceived failure of Western medicine. Such treatments were viewed as complementary rather than as an alternative to Western medication. Younger people, in particular, expressed considerable scepticism about the effectiveness of these traditional South Asian treatments (Ismail, Wright, Rhodes & Small, 2005).

Looking at the South Africa context, we see that approximately 80% of South Africans (WHO, 2002) consult traditional health practitioners when they experience imbalances in their lives (Gorjestanil, 2003; Kofi Akosah Sarpony, 2001). It is therefore necessary to consider indigenous knowledge when addressing the health challenges of epilepsy in historically Black schools in the Western Cape. Perhaps traditional healers could contribute in education to addressing the barriers to learning. The idea of drawing from community resources is endorsed by Department of Education, 2001a (Education White Paper 5).

*'Indigenous knowledge' is often associated in the Western context with the primitive, the wild, and natural. Though, for others, especially the millions of indigenous people of Africa, Latin America and Asia, indigenous knowledge (or what they have called the 'native ways of knowing') is everyday rationalisation that rewards individuals who live in a given locality (Somali, 1999).*

This study builds on the study conducted by Keikelame and Swartz about parents' understanding of the causes and management of their children's epilepsy in Khayelitsha, one of the biggest townships in Cape Town in the Western Cape, South Africa (2007, 37(2):307-315).

The study explored what parents believed to be the cause of their children's epilepsy and how they managed the condition. The findings were that most participants did not know the cause of their children's epilepsy. The known medical causes were meningitis, tumour and heredity. The study also revealed a lack of understanding of the correct use of seizure medication, the appropriate use of first aid measures and the importance of disclosing the condition and having regular check-ups. Some participants reported that they had used traditional and Western treatments. Some participants believed their children's epilepsy was caused by evil spirits (amafufunyane) and bewitchment. As a result, they were afraid to associate themselves with their children. Since this study focused mainly on the home situation, it was felt that questions around what happens at school had not been answered and this prompted the researcher to explore this aspect through the current study.

Since the policy of inclusive education as set out in the Department of Education 2001b (Education White Paper 6) is expected to be implemented in South African schools, learners with epilepsy are expected to be educated alongside their peers in regular mainstream schools with the required support. Inclusive education is an important instrument in providing each learner with a sense of belonging, and encouraging the respect for differences among learners. *The goal of inclusion is not to erase differences, but to enable all learners to belong within an education community that validates and values their individuality* (Stainback, East & Sapon-Shevin, 1994:489). Inclusive education regards each learner as an individual who needs to be accepted, instead of assigning labels that categorise and excludes them. I believe this policy will really benefit learners with epilepsy. It will have various educational, social and economic advantages and will eliminate the injustice of labelling. Hence this study wants to focus on getting educators, parents and learners to better understand epilepsy and how it impacts learners in the school environment and thereby contribute to the facilitation of the inclusion of learners with epilepsy. It seems that some educators, parents and learners lack information about epilepsy and the behaviours associated with an epileptic seizure. Seizures manifest differently according to the varying types of epilepsy and this can be confusing. A lack of understanding of what exactly epilepsy is all about can create a barrier to learning, especially for those living with the condition. All learners living with epilepsy need to be

educated to help them develop supportive relationships and prepare them for managing their condition in the school environment. Through *inclusion* we can reduce fears, build friendships and nurture respect and understanding.

## 1.5 RESEARCH AIMS AND QUESTIONS

### **The aim of the study:**

The aim of the study is to understand the existing level of knowledge of epilepsy among those in the school environment in order to develop a training programme that will educate teachers and parents about epilepsy and equip them with the necessary knowledge and skills for its management.

### **Research Questions:**

This study was guided by the following questions:

1. *What do learners, parents and educators understand about epilepsy?*
2. *What is the experience of the learner with epilepsy in the mainstream school?*
3. *What interventions does a school provide for learners with epilepsy?*
4. *What are the educators' perceptions about including learners with epilepsy in mainstream schools?*

## 1.6 RESEARCH DESIGN

In order to investigate the research problem I elected to work in the interpretive research paradigm and do a qualitative study. According to Merriam (1998) the purpose of this type of research is "to understand how people make sense of their lives and experiences, and how they construct their worlds". It was felt that this method would be best suited for my research problem as *it values the participants' perspectives on their world and seeks to discover those perspectives* (Merriam, 1998). Since the focus is on understanding people in terms of their own definition of the world; *the focus is on the insider perspective rather than on an outsider perspective* (Mouton, 2001).

## **Research Methodology:**

### **Participants**

The participants were selected by means of purposive sampling. This technique involved the selection of typical or interesting cases of people who had epilepsy and those who had some experience with the illness. The participants were selected from four primary schools in the Khayelitsha township in the Western Cape. Four learners living with epilepsy, their parents and five educators from each school were selected.

### **Data collection**

Data were collected by means of semi-structured interviews. A semi-structured interview allows the subject to provide as much information as possible for the study. I chose this technique because I wanted to determine how different individuals (educators, parents and learners) understood epilepsy. Interview schedules were developed, namely one for the teachers, one for the parents and one for the learners (Addendum 1). The interview schedule was translated from English into Xhosa as this helped the participants to express themselves freely using their mother tongue. In total, twenty-eight interviews were conducted.

### **Data analysis**

Data were analysed under the headings of the research sub-questions using thematic analysis. Thus *the inductive analysis was used to discover patterns, themes and categories* (Patton, 2002).

### **Ethical considerations**

This research was firmly grounded in ethical practice. This included the right to privacy, which was respected. Before the study commenced, participants were informed about the study in both Xhosa and English. They were informed that their participation was voluntary and that they had the freedom to withdraw at any time. Educators, parents were asked to sign a consent letter while learners were given assent letter, as proof of them agreeing to be part of the study. Participants' roles were discussed before the research took place and they were assured of confidentiality and respect for their safety, risk and trust. A letter requesting permission to do this research at the selected schools was submitted to the Western Cape Education Department. Permission was granted and the principals of these schools were notified. The study was also submitted for ethical clearance to Stellenbosch University's Ethics Committee and ethical clearance was granted. The reference number is **210/2009**.



## 1.7 DEFINITION OF KEY TERMS

### 1.7.1 Epilepsy

Epilepsy is described as experiencing recurrent seizures. Seizures are the result of a temporal breakdown in the brain's communication system, caused by abnormal disorderly brain cell activity. Most seizures are accompanied by altered level of conscious, confused behaviour and change in sensory exposure (Baddeley & Ellis, 2002:7; Frieman & Settel, 1994:198). Learnard and George (1999:73) describe a seizure as follows:

*A seizure is a convulsion or brief abnormal event resulting from a raging discharge of cerebral neurons. Epilepsy is the continuing tendency to have such seizure, even if a long interval separates attacks. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. It's also called a seizure disorder. When a person has two or more seizures, they are considered to have epilepsy. A seizure happens when a brief, strong flow of electrical activity affects part or all of the brain. One in 10 adults will have a seizure sometime during their life.*

### 1.7.2 Historically Black Schools

Historically Black schools were schools which under the apartheid government were segregated schools situated mainly in residential areas populated by people classified as Black for the exclusive use of people in this racial classification category.

Many started off as denominational schools established by various religious associations to provide education experiences to children of Black South African communities. These schools were responsible for offering education to (almost exclusively) Black South Africans until the promulgation of the Bantu Education Act of 1953. The underlying assumption was that Blacks had a different culture to Whites, and that they had to be educated accordingly. *Black education initially had a strong missionary presence, especially in the rural areas. However, the rigid way in which the policy was applied eventually led to much discontent and hardship in these schools. These schools were subsequently controlled by the government.* ([HSRP@historicsschools.org.za](mailto:HSRP@historicsschools.org.za)).

### 1.7.3 Indigenous Knowledge

Indigenous Knowledge reflects the dynamic way in which the residents of an area have come to understand themselves in relation to their natural environment and how they organise knowledge, cultural beliefs and history to enhance their lives (Colomenda & Wenzel,

2000:244). The explanation of indigenous knowledge needs to incorporate the meaning of 'indigenous' and 'indigenous people'. The concept indigenous refers to "the 'natural' occurrence or innateness, of a people to a region" (Suzuki & Knodston, 1992:6). It is a term used by the United Nations in its recognition of the special or unique rights of inhabitants of a place.

#### **1.7.4 Inclusive education**

According to Green (2001:4), inclusive education is a term used *to describe educational policies and practices that uphold the right of learners with disabilities to belong and learn in mainstream education.*

### **1.8 OUTLINE OF THESIS**

The study is organised as follows:

- Chapter 1: Provides the introduction, background and motivation of the study focusing on the needs, social problems, research gap and particular question. The summary process of the research methodology is discussed. Definitions of keywords used within the context of the study are provided.
- Chapter 2: Focuses on the literature review of relevant areas of the study. Firstly epilepsy will be discussed, and then Constructivism. This will be followed by a look at indigenous knowledges, other cultural beliefs and some empirical research conducted. Lastly, inclusive education will be discussed.
- Chapter 3: Presents a detailed description of the research methodology of this study and gives a justification for the use of the qualitative approach and selected data collections methods.
- Chapter 4: This concluding chapter will comprise of a presentation, analysis and discussion of the findings. Finally, it will offer recommendations for learners living with epilepsy and for their educators.

## CHAPTER 2

# LITERATURE REVIEW

### 2.1 INTRODUCTION

This chapter will outline the theoretical framework and review the literature on epilepsy, constructivism, indigenous knowledge and cultural beliefs on epilepsy. It will also look at an overview of the inclusive education to explore how epilepsy is understood, the experiences of learners and the level of support they receive in a historically Black school.

### 2.2 AN INTRODUCTION TO EPILEPSY

#### History of epilepsy

Epilepsy has been known since ancient times. Epilepsy is an English word derived from the Greek word "epilepsia" meaning to "take hold of" or "seize". For centuries, epilepsy was regarded as a sacred disease that originated from demons or evil. Most people believed that when a person had a seizure, he/she was trying to get rid of demons. They believed it was contagious and often regarded people with epilepsy as insane (Chokroverty, 1996). Feldman, Gordon and Snyman (2001:125) point out that *the word epilepsy carries disturbing connotations and is a frightening condition about which there are many misconceptions, mysticism, magical powers, and demonic spirits due to its invisibility and sudden onset, causing fear in both the onlooker and the sufferer.*

The first person who moved away from the mythology associated with epilepsy was the Greek physician Hippocrates. He defined epilepsy *as a neurological condition caused by a disturbance in the brain* (Fritz Dreifuss, 1996).

### 2.3 WHAT IS EPILEPSY?

*Epilepsy is an altered chemical state of the brain causing bursts of excessive electrical activity. The sudden bursts of this electrochemical activity scramble the brain's messages upsetting the brain's normal control. These may be characterised by distorted consciousness, motor activity, sensory phenomena, or inappropriate behaviour* (Kapp, 1991). Epilepsy is not contagious; it cannot be passed on to other people. *It is a very serious, at times life-*

*threatening condition, and is not a mental illness such as depression. Although it cannot be cured, it may be controlled through medication and even surgery (Landsberg et al., 2005).*

### **2.3.1 Prevalence**

The "prevalence" of a condition refers to the number of people who currently have the condition. Prevalence of epilepsy is difficult to be ascertained, for a number of reasons. Prevalence has yielded variable results according to the methodology, sampling and definition of epilepsy used for individual studies. Some studies include single, isolated seizures and it has been noted that some learners are reluctant to divulge their epilepsy due to social stigma. It has been found that some learners with positive diagnosis deny their epilepsy publicly (O'Donohoe, 1994:3-4; Sharvon, Hart, Sander & Van Andel, 1991:1). However, September Epilepsy South Africa (2004:1) asserts that 1% of the world population suffers from epilepsy. He further maintains that there is no current static data on the prevalence in South African schools. This accords with the research conducted in Groote Schuur Hospital in Cape Town where the findings were that epilepsy is the most common condition of the brain, and that about 1 out of 100 people have epilepsy. (Retrieved from Division of Neurology, Groote Schuur Hospital, Cape Town, South Africa, 2004 [www. reastman@uctgsh1.uct.ac.za](mailto:reastman@uctgsh1.uct.ac.za)).

### **2.3.2 Causes of epilepsy**

Epilepsy can affect anyone at any age without apparent cause, and can cease just as suddenly. It is important to know that there are various conditions that may cause epilepsy. For example, in a child under five years old who experiences a seizure, the most common cause would be high temperature, above 39°C. This type of seizure, triggered by temperature, is known as **febrile convulsions/seizures**.

When the cause of epilepsy can be identified, we refer to this type of epilepsy as symptomatic epilepsy.

In **symptomatic epilepsy**, the seizures can be the result of intrinsic factors associated with physical illness, such as:

- Teething
- High fever
- Fatigue
- Head injuries
- Encephalitis

- Meningitis
- Metabolic disturbances
- Blood vessel abnormalities
- Cerebral bleeding
- Biochemical imbalances tumours of all kinds
- Lack of oxygen during birth
- A brain tumour
- Associated conditions such as cerebral palsy and autism
- Stroke
- Lead poisoning
- Infection of the brain.

In **Idiopathic epilepsy**, the seizure occurs without any reasons, but genetics is assumed to be the cause. It may be hereditary as sometimes more than one member of a family has epilepsy.

In epilepsy with **suspected cause**, extrinsic factors play a role and some possible triggers are:

- Drugs
- Alcohol
- Illnesses such as HIV and AIDS
- Nutrition shortage/malnutrition
- Flashing lights, TV patterns and loud sounds (Kapp, 1989)
- Tiredness, stress and excitement

**Cryptogenic epilepsy** occurs when no cause can be found. Unlike idiopathic epilepsy, it is believed that there is an undiscovered physical cause (Michael, 1995).

### 2.3.3 The different and characteristic forms of epilepsy

Different types of epilepsy have different characteristics, treatment and diagnosis. The kind of seizure a person has depends on which part of the brain is being affected by the electrical disturbance that produces the seizures. According to the International Classification system of Epileptic Seizures, epilepsy is categorised into three main types: **Partial Seizures**, **Generalized Seizure** and **Unclassified Seizures** (Kruger & Kapp, 2005).

#### **Partial Seizures**

Partial Seizures are divided into **simple partial**, **complex partial** and **partial seizure with secondary generalisation**.

**Simple partial:** when a small part of the brain is affected by a seizure, a simple partial seizure may occur. When the person experiences this type of seizure, s/he will be aware of everything around her/him. The person may feel a tingling sensation of twitching or have a strange feeling in his/her stomach. He/she may be able to smell strange smells or have an odd taste in the mouth. According to Heller *et al.* (1996), simple partial seizures sometimes develop into other types of seizures and the simple partial seizure is then referred to as an aura or warning of another seizure.

**Complex partial:** This type of seizure may take many different forms. During this type of seizure a person will not be totally aware of what is going on around them and may often act in a very confused way. The person may fiddle with his/her clothes or even undress. Sometimes a person may move or walk around and he/she could be injured.

**Partial seizure with secondary generalisation:** This seizure is when the electrical activity in the brain continues to spread as a result of the partial seizure. This type of seizure involves the whole body.

### **Generalized Seizures**

A general seizure is a loss of consciousness and abnormal behaviour. The muscles in the body tense up, the limbs and the body become stiff and breathing stops. During the seizure a great deal of excess saliva can be produced causing foaming at the mouth. The eyelids stare or squint and the lips turn blue. After 20-30 seconds, violent jerking shakes the body and the person sometimes wets him/herself. Before the person can gasp breathing, normal colouring returns to the face. The person then relaxes into unconsciousness and consequently confused consciousness with no knowledge of what has happened. After a seizure has occurred the person may have a bad headache, feel tired and need to sleep. The seizure pattern differs from person to person. The duration of each phase lasts no longer than three minutes (Landsberg *et al.*, 2005).

There are two types of general seizures, namely **non-convulsive general seizures** and **convulsive general seizures**.

### **Non-convulsive seizures**

The convulsions are absent. **Absence seizures** - also known as petit-mal seizures, can be typical or atypical:

- **Typical:** with this seizure a child will suddenly lose consciousness, stop what he/she is doing, stare and roll the eyes upwards. As the child completes the process, he/she will resume his/her previous activity as inching occurs. Absence seizures can occur a number of times a day. A typical seizure usually last a few seconds, rarely continuing for more than 30 seconds.
- **Atypical:** is a type of seizure associated with change in muscle tone. It may be accompanied by rapid blinking and chewing of the mouth. This seizure can result in learning difficulties if not recognised and treated.

### **The convulsion seizures**

There are various phases of convulsion seizures, known as **tonic, clonic, coma, myoclonic** and **atonic** phases.

- A. Tonic:** When a person experiences this phase, his/her trunk stiffens, the wrists contract, breathing stops, air is exhaled from the lungs, and eyes are half open, while the eyelids and jaws are stiff. Groaning or grunting sounds may be made or an 'epileptic scream' may occur while air is exhaled from the lungs.
- B. Clonic:** A person experiencing this phase begins with violent, rapid spasms which end in irregular jerks. These can be accompanied by loss of sphincter control. Respiration is resumed slowly and foam may appear at the mouth. The patient sometimes tends to bite his/her tongue or the inside of his/her mouth during a seizure and consequently the foam may be bloody.
- C. Coma:** This is a deep unconsciousness or coma. The muscles relax gradually, the limbs relax and the person sometimes goes into an ordinary form of deep sleep (Kruger & Kapp 2005).
- D. Myoclonic:** According to Murphy and Dekhargan (1994) the myoclonic seizure is very brief sudden muscle contractions that occur alone or in clusters. The limbs, or a limb, may jerk, possibly causing the person to fall. It may be one or multiple jerks in a variable period of time. According to Hanscomb and Hughes (1995) myoclonic seizures occur in the morning, specifically within a few hours of waking up.

### **The following are other types of myclonic seizures:**

- **Typical myclonic of early childhood:** This seizure develops in children from the age of 6 months to 11 years. The seizure may vary from several times a day to once a week.

- **Complex myclonic of early childhood:** This seizure is accompanied by several disorders such as microcephaly. It causes delays in the child's milestones.
- **Juvenile:** Epilepsy that begins in adolescence. The seizures are mild and they involve the hands and arms; the adolescent may spill or drop objects.
- **Infantile spasms:** This type of seizure is a cluster of quick, sudden movements that begin when children are between 3 months to 2 years of age.

**E. Atonic:** A child or adult suddenly collapses and falls. After 10 seconds to a minute he/she recovers and regains consciousness and can walk again as if nothing happened.

### **Unclassified Seizures**

An unclassified seizure is a seizure which cannot be classified because there is a lack of enough information to indicate what type of seizure it is (O'Donohoe, 1994:9).

## **2.4 DIAGNOSIS OF EPILEPSY**

There are no physical signs that a person has epilepsy. Unlike most neurological disorders, the diagnosis of epilepsy is largely clinical; therefore an accurate description of the seizures and the circumstances in which they occur is most important. These descriptions will probably be provided by friends or relatives who have witnessed the seizure. This will help in the diagnosis and may determine the need for further investigations such as:

- Blood tests which will help the doctor assess the general health of the person and will eliminate other potential causes of seizures.
- CAT Scans (Computerised Tomography) may be taken to determine whether or not there are any structural changes in the brain.

EEG (Electroencephalogram) will measure changes in the brain's functioning, detected by alterations in electrical activity (Landsberg et al., 2005).

It is quite possible that any, or all, of these investigations will record "normal" results, but on the basis of observed symptoms, a diagnosis of epilepsy can still be made. Various criteria are used to help with the diagnosis of epilepsy.

### **2.4.1 Medical history**

The most important information for the doctor is gleaned when the person describes what he/she has experienced. He/she will be asked to give an accurate description. It is important



that an accurate eyewitness account should be made as the learner experiencing a seizure usually has no recollection of what has happened. The diagnosis is made on the basis of the history of more than one epileptic seizure.

#### **2.4.2 Blood test and brain scans**

The blood test checks the general health of the person and helps diagnose the exact cause of the seizure. Brain scans provide X-rays and other detailed pictures of the brain that may show damage.

#### **2.4.3 The Electroencephalogram (EEG)**

The Electroencephalogram (EEG) is the most specific test for the diagnosis of epilepsy. According to Kruger and Kapp, its purpose is to make a recording of the brain activity or brain waves. If the disturbance of the brain occurs in various anatomical areas of the brain, and is caused by various factors, the electroencephalogram (EEG) will pick up any unusual brain activity and can help identify what type of seizure it is. Small discs, called electrodes, are applied to the person's scalp to record electrical activity in the brain.

### **2.5 EDUCATIONAL PROVISION FOR LEARNERS WITH EPILEPSY**

In South Africa, as in most countries, learners with epilepsy attend mainstream schools. In South Africa the precise number of learners with epilepsy is not known. Many educators of these learners are not even aware that they have epilepsy. As cited by Johnson and Parkinson (2002), a child with epilepsy usually makes a high demand on the educator and because the educator doesn't know that this is a learning barrier, he/she will often become irritated with the child. This lack of awareness can lead to various educational problems and risks around health management.

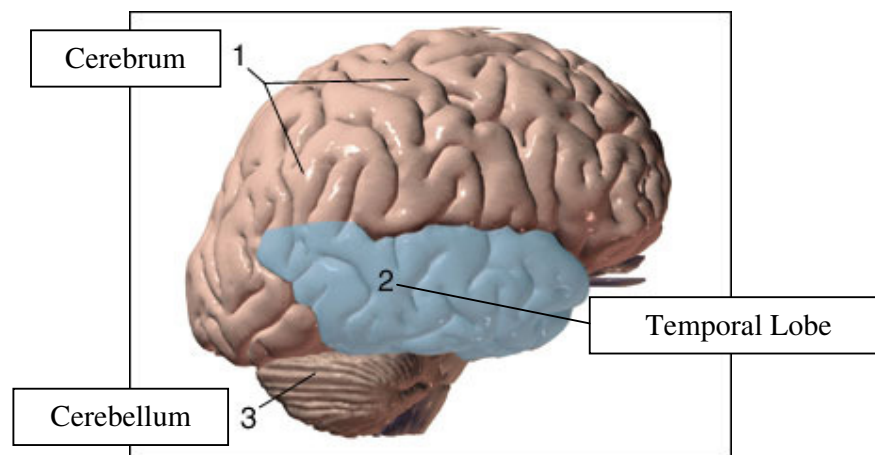
#### **2.5.1 Education implications of epilepsy**

It is every school's responsibility to acquaint itself with the different types of epilepsy to be prepared for any challenges regarding learners with epilepsy. Johnson and Parkinson (2002) state that some educators do not associate poor school achievement with epileptic manifestations and are not familiar with the side effects of medication. Looking at the possible effects of epilepsy on teaching, Michael (1995) believes that epilepsy inevitably indicates learning problems. Hermann and Whitman (1984; Rodin, 1989) found that cognitive functions controlled by the area in which the specific epilepsy is located, could be affected.

The effects of epilepsy on a learner depend on the type of epilepsy as well as the incidence and duration of the seizures.

*When teaching a learner with epilepsy, it is important for the educator to understand, with the help of the parent and medical profession, the area of the brain in which the epileptic activity is occurring* (David Lewis Centre for epilepsy, 1997). This will help the educator to understand the effect of the seizure on the learner. Most studies have shown that many learners with epilepsy whose seizures began at the temporal lobe have memory impairment.

The temporal lobe is the largest part of the brain after the cerebrum and is divided into four paired sections - the frontal, parietal, occipital, and temporal lobes. Each lobe controls a specific group of activities. The temporal lobe, located on either side of the brain just above the ear, plays an important role in hearing, language and memory. In people with temporal lobe epilepsy, the area where the seizures start, the "seizure focus", is located within the temporal lobe. Temporal lobe epilepsy may, for example, cause sudden outbursts of unexpected aggression or agitation, or it may be characterised by aura-like phenomena. This is the most common type of epilepsy in teens and adults (Last Editorial Review, 2/5/2004). The picture below illustrates the positioning of the temporal lobe.



Source: [http:// www.gemma.davies.com/.html](http://www.gemma.davies.com/.html) Retrieve on the 20 June, 2009.

Gordon and Mc Kinlay (1986) cited that many learners with epilepsy whose seizures began at the temporal lobes have memory impairment. This impairment can have a negative impact on learning and could raise a need for remedial strategies.

The following is a typical narrative of a person with temporal lobe seizures:

*"I get the strangest feeling. Most of it can't be put into words. The whole world suddenly seems more real at first. It's as though everything becomes crystal clear. Then I feel as if I'm here but not here, kind of like being in a dream. It's as if I've lived through this exact moment many times before. I hear what people say, but they don't make sense. I know not to talk during the episode, as I just say foolish things. Sometimes I think I'm talking but later people tell me that I didn't say anything. The whole thing lasts a minute or two"* (Retrieved from EBSCO Culture different views on epilepsy, 2008).

Experiences during temporal lobe seizures vary in intensity and quality. Sometimes the seizures are so mild that the person barely notices. In other cases, the person may be consumed with fright, intellectual fascination or even pleasure. The experiences and sensations that accompany these seizures are often impossible to describe, even for the most eloquent adult. And of course it is even more difficult to get an accurate picture of what children experience.

Educators should be aware of learners suffering from frontal lobe epilepsy as this may result in them misinterpreting the learner's behaviour as not paying attention, daydreaming or numerous other explanations for which the learner may be reprimanded. The school should take note that every learner is a unique individual. As already discussed, educators need to understand which type of epilepsy different learners have and schools need to commit to working systematically in order to understand their learners better. According to Bronfenbrenner (1996) working systemically means, as illustrated in his model, bio-ecological systems which interact with each other in a reciprocal way. The bio-ecological model has had a major influence on understanding families and schools as well as the relationship between them and within their social contexts. In the bio-ecological model, Bronfenbrenner (1917-2005) shifts the focus away from seeing the child as having a disability. His analysis is that there are interactions between systems that impact on the child and "create the disability". This means that the school, the learner with epilepsy and his/her family should work hand-in-hand in attempting to understand how his/her development is shaped and influenced by his/her context. According to Jordaan and Jordaan (1989), taking the context into account sheds new light on information. The way people experience their environment influences the way they act within it, and their actions in turn influence their experience of the environment. Therefore, it is also important to understand the individual in relation to his/her social context, and to understand how individuals construct their knowledge according to this context.

## 2.6 INDIGENOUS KNOWLEDGE

### Introduction

*Indigenous Knowledge reflects the dynamic way in which the residents of an area have come to understand themselves in relation to their natural environment and how they organise the knowledge, cultural beliefs, and history to enhance their lives (Semali & Kincheloe, 1999).* In this section I will highlight the nature and importance of including indigenous knowledge in the school environment.

#### 2.6.1 What is Indigenous Knowledge?

Indigenous Knowledge can be broadly defined as the knowledge that an indigenous local community accumulates over generations of living in a particular environment. This definition encompasses all forms of knowledge technologies, know-how skills, practices and beliefs that enable the community to achieve stable livelihoods in their environment. Colomeda and Wenzel (2000:24) explain that *Indigenous people shall be people living in countries which have population composed of different ethnic or racial groups who are descendents of earliest population which survived in the area, and who do not as a group, control the national government of the countries within which they live.*

According to the South African context, indigenous knowledge refers to traditional knowledge that is handed down from generation to generation in communities based on experiences and adaptation over time. This knowledge continues to develop. *Indigenous knowledge is attributed to a particular group relating directly to the environment in which people live and is viewed as an ongoing process (Hasen & Van Fleet, 2002).*

#### 2.6.2 Why is Indigenous Knowledge important?

*In the emerging global economy a country's ability to build and mobilise knowledge capital is equally essential for sustainable development as the availability of physical and financial capital (World Bank, 1997).* The basic component of any country's knowledge system is its indigenous knowledge. It encompasses the skills, experiences and insights of people, applied to maintain or improve their livelihood.

Indigenous knowledge is developed and adapted continuously to gradually changing environments and passed down from generation to generation, closely interwoven with people's cultural values. Indigenous knowledge is also the social capital of the poor, their

main asset to invest in the struggle for survival, to produce food, to provide shelter or to achieve control of their own lives.

### **2.6.3 Indigenous knowledge: International context**

Indigenous people around the world are fighting for the right to have historically acceptable indigenous world views and practices acknowledged, respected and valued in their own right at personal, community and political level. This statement was endorsed between 1996 and 1997 when an International Consortium for Indigenous Knowledge (ICIK) was held at Pennsylvania State University Campus. Many debates and questions emerged around the notion of indigenous knowledge and how it is valued and used in the community. One point that was highlighted was that indigenous knowledge does not exist in a vacuum; it belongs to a community. In this regard, educators, scientists and learners have to take notice that access to this knowledge is gained only through contact with that community (Semli, 1999).

In some countries, traditional healing approaches are the main resource for addressing the various problems relating to health and well-being, while in other countries - including many 'western' societies - traditional healers and 'western' medical practitioners are often consulted simultaneously. Gorjestanil (2003) and Kofi Akosah-Sarpony (2001) affirm this by saying *Utilizing indigenous knowledge helps to increase the sustainability of development efforts, because the traditional integration process provide for mutual learning and adaptation, which in turn contributes to the empowerment of local communities.*

### **2.6.4 Indigenous knowledge in South Africa**

Since 1994, much has been said about indigenous knowledge and its role in a democratic South Africa, although little seems to have been achieved in the way of integrating indigenous knowledge within a democratised South Africa. The government has taken some initiatives to recognise the importance of indigenous knowledge in South African communities. One example is the Department of Science and Technology's development of an Indigenous Knowledge Systems (IKS) Policy meant to give indigenous knowledge the respect it deserves and to address the injustices of apartheid towards indigenous knowledge systems.

The Department of Health has also taken some significant steps to include indigenous knowledge in the health system, emanating from the escalating HIV and AIDS pandemic in the country. A Bill was passed by Parliament to regulate the practice of traditional healers (Government Gazette, 2003). In November 2004, the Arts and Culture Portfolio Committee of

the Parliament of South Africa approved the Indigenous Knowledge Systems (IKS) Policy for South Africa. The policy consisted of four key areas:

1. Affirmation of African cultural values in the face of globalisation.
2. Development of services provided by indigenous knowledge holders and practitioners.
3. Contribution of indigenous knowledge to the economy
4. Interfacing with other knowledge systems.

The four focus areas were mostly prompted by two key problems facing Africa:

- Poor health, including HIV/AIDS
- Poverty, including food insecurity.

The African population is one that uses traditional medicines to meet their healthcare needs. Globally and throughout Africa, indigenous knowledge has interfaced with other knowledge systems, in particular the dominant paradigm of 'Western scientific knowledge'. According to Hart and Vorster the interaction has largely been in the health sector and, given the commodity orientation of the capitalist economic system,' indigenous' populations in South Africa, particularly elders and traditional healers. Traditional healers were consulted for their knowledge of the medical properties of various plants. Many Africans in South Africa realise that traditional medicine and its practitioners are markedly under-utilised. *It is estimated that in South Africa there are more than 20 000 indigenous healers* (Gilbert, Selikow & Walker, 2002). The value of this knowledge cannot be underestimated because it has been helpful in remedying various health problems such as epilepsy, HIV and AIDS and other illnesses. For example, a person with epilepsy symptoms would be sent for treatment to various ministers, priests, spiritualists, practitioners, and herbalists based on the evident symptoms. These alternatives were also sought by those already using conventional treatment such as anti-seizure drug therapy. Unfortunately, there was a lack of consistency when taking the medication. Alternative therapies were also sought if conventional medications were not controlling the seizures, because it was thought that the illness may not only be medical in nature.

This statement is linked to research conducted on religious beliefs. The research aimed at exploring the influences of spiritual and religious beliefs on the explanation of the cause of epilepsy, and the choice of treatment in people of South Asian origin that have epilepsy. A total of 20 Muslims (10 male and 10 female), six Sikhs (two male and four female) and four

Hindus (three male and one female) accepted the invitation. The age range was 18–68 years, with 18 respondents aged below 35 years. Five respondents classified their occupation as professional/managerial, six as skilled or unskilled manual, nine as housewives, eight as retired or unemployed, and two as university students.

The results were as follows: half the respondents attributed their illness to fate and the will of God, or as punishment for sins of a past life. Other patients had experienced prejudice from people who believed that their epilepsy was contagious. A strong network of traditional healers was found, providing a parallel system of healthcare in the UK and on the Indian subcontinent. People turned to religion and spiritual treatments in desperation for a cure, often under the influence of their families after the perceived failure of Western medicine. Such treatments were viewed as complementary, rather than as an alternative to Western medication. Younger people in particular expressed considerable scepticism about the effectiveness of these traditional South Asian treatments (Ismail et al., 2004).

The researcher's conclusion from the South Asian sample was that people commonly turned to traditional healers in search of better health. *Health professionals should be aware of the belief systems of these patients and understand the types of treatments in common use. Although these treatments might potentially compete with Western health care, they are used as an adjunct rather than a substitute. Patients have a 'healthy' scepticism about the effectiveness of such treatments, and adherence to medical therapy does not appear to be affected* (Ismail et al., 2004). Let's examine how other cultures construct and view epilepsy according to their context:

## **2.7 AFRICA'S CULTURAL VIEW ON EPILEPSY**

Africa is a diverse continent that presents people of different cultural backgrounds. It is important to note that all beliefs and perceptions explored here are generalisations based on studies and surveys done in the past and do not, by any means, apply to individual cases. Each individual is unique and may hold traditions and beliefs unfamiliar to others of the same culture. In Africa, the concept and cause of disease and the aim of healing focused on three aspects: magic or spiritual, empirically determined conditions and psychological phenomena. These aspects are therefore directly linked to spiritual, physical, social and psychological factors. Illness is caused by an imbalance of any of the above (Department of Health, 2000).

### 2.7.1 Epilepsy in Africa

An article on *Epilepsy in Different Cultures* written by Andermann (1999) looks at how epilepsy has been viewed differently by other African countries. The research conducted on culture-sensitive healthcare attitudes towards epilepsy in countries such as Nigeria, Uganda, Cameroon, Malawi, Swaziland and Ethiopia mentioned that various traditional beliefs pertaining to epilepsy and its causes and treatments were uncovered. Interestingly, the stigma associated with epilepsy among African communities is not as drastic as that found within other cultures; however, it does exist. Africans living with epilepsy do feel that there is a difference in the way they are treated by society, as well as by family and friends. In the general community, problems exist in the form of job discrimination and isolation. With respect to family and friends, overprotection and restriction of activities interfere with their daily lives, as they are often seen as socially and intellectually less capable than others. Stigmas are often associated with fear. Among the African community, there is often a fear of witnessing a seizure. When asked why they fear this, many people reported that they are afraid as they don't know what action to take when seeing someone in a seizure state. ([www.diversityresources.com/health2k/health/african2.html](http://www.diversityresources.com/health2k/health/african2.html)). It is precisely these beliefs, however, that prevent 80% of epilepsy patients in Africa from receiving correct treatment.

The diagram below illustrates the findings of studies on how other African countries perceived and understood an individual with epilepsy:



| COUNTRY   | SPECIFIC IMPRESSIONS   | SPECIAL HERBAL/SPIRITUAL REMEDIES  |
|-----------|--|--|
| Uganda    | <ul style="list-style-type: none"> <li>Epilepsy is called <i>ensimbu</i> and refers to tonic-clonic (grand mal) seizures</li> <li>Epilepsy thought to be contagious</li> <li>illness brought on by <u>witchcraft</u></li> <li>a lizard spinning around in circles in the head is disturbing the brain causing dizziness, usually followed by a seizure</li> <li>social constraints; sometimes the person has to eat and sleep alone, leave school, not play with other children and, most likely, not marry</li> </ul> | <ul style="list-style-type: none"> <li>because <i>ensimbu</i> is thought to be a result of witchcraft, it is believed that western medicine is not effective</li> <li>to treat the lizard in the brain, cupping is used to remove the lizard, along with additional medication</li> <li>severe burns are used by physicians as an aid in diagnosing epilepsy, since cooking fires are so common in Africa, and people convulsing fall into the fires</li> <li>according to traditional healers, burns are a sign that the disorder is incurable</li> </ul> |
| Cameroon  | <ul style="list-style-type: none"> <li>Epilepsy thought to be contagious and brought on by witches</li> <li>epilepsy is known as <i>nwaa</i> or "to throw a person on the ground."</li> <li>the term also refers to saturation of the foams in the stomach which overflow and rise to the head, resulting in a seizure</li> <li>people with epilepsy are "those who die and are resurrected" and are thought to be possessed by the devil</li> </ul>   | <ul style="list-style-type: none"> <li>traditional healers are consulted</li> <li>a special diet is assigned to control the foam being produced in the stomach</li> </ul>  |
| Malawi    | <ul style="list-style-type: none"> <li>An insect moving inside the stomach is thought to cause epilepsy</li> </ul>   | <ul style="list-style-type: none"> <li>traditional healers, with their mixtures of roots, are consulted</li> <li>these mixtures induce vomiting which is thought to rid the stomach of the insect</li> </ul>   |
| Swaziland | <ul style="list-style-type: none"> <li>Epilepsy is known as <i>sifosekuwa</i> (falling disease) or <i>sitfuluwane</i> (lizard's movement)</li> <li>caused by sorcery, which sends evil animals or spirits into the body, causing convulsions</li> </ul>  | <ul style="list-style-type: none"> <li>therapies work to purify and protect</li> <li>therapies include enemas, inhaling medical fumes, vomiting, sneezing and exorcism</li> </ul>  |
| Ethiopia  | <ul style="list-style-type: none"> <li>Epilepsy is known as the <i>Aspinning</i> or Arotary illness</li> </ul>   | <ul style="list-style-type: none"> <li>holy waters, priests and spirit specialists (dealing with exorcism and sacrifices) are visited</li> <li>charms and traditional remedies</li> <li>patients do not visit a hospital for up to five or six years because of societal pressures and a belief in spiritual therapy</li> </ul>  |

Retrieved on 15.06.2009 from [www.diversityresources.com/health2k/health/african2.html](http://www.diversityresources.com/health2k/health/african2.html)).

The way knowledge is constructed differs from person to person. The table above shows how different cultures understand and view epilepsy. In this regard, educators should be aware that dealing with learners from different backgrounds means they need to have a broadly understanding of the condition. The learner's background can influence how he/she makes sense of things. Educators should also acknowledge that learners are always at the centre surrounded by different systems that influence and impact on how they perceive things. Schools have to develop alternatives and adaptations to accommodate all learners' diverse needs. In the case of learners with epilepsy, the school should take note of the benefits of inclusive education.

### **Characteristics of Western views on health and epilepsy**

In South Africa in the past, Western views on the approach to medicine was generally recognised and respected to the exclusion of African traditional approaches. As a result, Western orthodox bio-medicine still benefits from government support while the latter approach has only recently been acknowledged as appropriate to the South African context (Bikka, 2005). Western orthodox bio-medicine views the human body as a machine with parts that can be 'fixed' separately from the many other influences impacting on the individual (Good, Hunter, Katz & Katz, 1979). This approach is often costly, lacks a proactive perspective, does not encourage self-empowerment and views the patient as a passive being.

Modern Western medicine is based on the biomedical approach that assumes the following:

- The mind and body can be treated separately
- It adopts a mechanical metaphor, which compares the body to a machine
- Medicine adopts a technical imperative
- The explanation of illness focuses on biological changes to the relative neglect of social and psychological factors
- It assumes that every disease is caused by a specific, identifiable agent namely a 'disease entity' (Nettleton, 1995).

### **Western Medicine's Treatment of Epilepsy**

Treatment usually involves reacting to and suppressing symptoms rather than encouraging self-healing illness prevention (Thomas, 2000). As mentioned before, the human body is compared to a machine and therefore the treatment is focused on 'fixing' this machine. The mechanical metaphor adopted by this view of health assumes that doctors can act like

engineers to mend whatever is dysfunctional (Nettleton, 1995). It seems that biomedicine does not take into account the impact of society and the environment on the health of an individual. *For an orthodox bio-medical practitioner, symptoms suppression is the norm and he/she usually adopts an approach to the treatment involving medication and/or surgical procedures, which are very often the first, if not the only choice. The underlying questions of what exactly is the source of the clinical disorder, and how this should be addressed in order to prevent further recurrence, receives scant attention* (Mc Taggart, 1996). With this in mind it can therefore be assumed that the treatment of epilepsy is mainly concerned with suppressing the symptoms of an 'illness'.

### **Medication for epilepsy**

*Convulsions can be treated by using phenytoin* (Annual report, Epilepsy Foundation, 2006). An early recognition of seizures and regular, consistent treatment with anti-convulsant drugs such as phenytoin offers the best chance of normal development and a positive future for the child with epilepsy. If a child is diagnosed with epilepsy at a young age it does not mean that he/she is necessarily going to outgrow the condition. It still needs to be treated with medication and youngsters should be encouraged as early as possible to be responsible for taking their own medication. If medication is in liquid form, the bottle should be shaken well before the dose is poured. If this is not done, the effective part of the medication may sink to the bottom, making the first doses too weak and the last ones too strong.

When medication is prescribed, the doctor should explain clearly if it needs to be taken before, during or after meals. Sometimes medication on an empty stomach can increase the possibility of stomach upset. On the other hand, taking certain drugs after food may affect the rate at which the drug is absorbed into the blood stream (Annual report, Epilepsy Foundation, 2006).

The standard treatment for epilepsy is the regular use of one or more chemical substances called anti-epileptic or anti-convulsant drugs. The ideal situation is when a person takes as little medication as possible while maintaining seizure control. Over the past decade there have been a number of developments, with new more-specific drugs becoming available.

### **Drug choices**

The table below contains information about the most commonly used anti-epileptic drugs. This is a summary and by no means a full description of the drugs. Special consideration must be given in respect of drugs for children with epilepsy as the effects of the medication may

differ from adults. When a person is on more than one type of medication, the drugs may influence each other and alter their effect. It is essential that the doctor should know about any other drugs a person with epilepsy is taking. A balanced diet, with adequate nutrients and daily water intake, is advised for optimal drug absorption. (Epilepsy South Africa is a Registered Non-Profit Organisation with Registration Number 001-911 NPO).

| <b>DRUG</b>   | <b>EPILEPSY/SEIZURE TYPE</b>   |
|---|--|
| <b>Carbamazepine</b><br>(Tegretol, Degranol)                | Simple and complex partial seizures, generalised tonic clonic seizures   |
| <b>Clobazam</b><br>(Frisium)                                | "Add-on" in tonic-clonic, myoclonic and partial epilepsies. Effective in catamenial epilepsy (menstrual seizures)  |
| <b>Ethosuximide</b><br>(Zarontin)                           | First or second choice for typical absences. May be effective in myoclonic seizures. Not effective in generalised tonic clonic seizures  |
| <b>Oxcarbazepine</b><br>(Trileptal)                         | Primary generalised tonic-clonic seizures and partial seizures.  |
| <b>Phenobarbitone</b><br>(Phenobarbital, Luminal, Gardenal) | Effective in generalised tonic-clonic, myoclonic and partial seizures. Effective in status epilepticus.  |
| <b>Epilim</b><br>(Sodium Valproate)                         | In the treatment of generalised epilepsy, particularly with the following patterns of seizures: <ul style="list-style-type: none"> <li>• absence</li> <li>• myoclonic</li> <li>• tonic-clonic</li> <li>• atonic</li> <li>• mixed as well as for partial epilepsy:</li> <li>• simple or complex seizures</li> <li>• secondary generalised seizures</li> <li>• specific syndromes (West, Lennox-Gastaut).</li> </ul> |
| <b>Epilim CR</b>  | For the treatment and prevention of mania associated with bipolar disorders.   |

The typical treatment of epilepsy is the use of medication called anticonvulsant drugs or anti-epileptic drugs. Many learners with epilepsy require daily administration of the medication during the school day. The current medication controls seizures very effectively. This means that the seizures may be kept to a minimum. It is important to note that medication does not only control seizures. Research indicates that there is a dramatic improvement in the schoolwork, self-esteem and behaviours of learners with epilepsy because they are no longer

at the mercy of the abnormal fluctuations in the activity of the brain (Kruger et al., 2001:70). It is important for educators to familiarize themselves with the different types of anticonvulsant drugs and their possible side effects. Treatment improves understanding of the condition; with the correct medication, most people with epilepsy may be able to lead full and active lives. The diagnosis may come as a shock and may enforce some drastic immediate changes but it is possible to lead a healthy lifestyle when living with epilepsy.

If the learner is on medication, the parents would need to inform the school so the educators understand the importance of managing the child's medication and can put mechanisms in place to ensure the safe and secure administration of this medication during school hours. According to a draft policy on the management of medication at special schools and public ordinary schools within the Western Cape (Discussed Document, December 2006) the need to provide guidelines does not only protect learners but also provides protection for the personnel at the school who may be involved in managing various medication processes. This policy focuses on what is expected and provides procedures for ensuring that all medication administered, kept and dispensed at special schools and public ordinary schools is done so in the best interest of the learner and the professionals responsible. Finally, it needs to be stressed that educators must know that epilepsy is not contagious; it cannot be passed on to other learners. It is a very serious, even life-threatening, condition that cannot be cured, but it can be controlled through medication, and even surgery (Kustscher, 2006).

### **African views of health and epilepsy**

#### **Characteristics of African traditional medicine in South Africa**

In contrast to Western medicine, African traditional medicine holds a holistic view of health that includes the individual's physical, mental, social and spiritual well-being. Similarly, illness is also dealt with holistically and the aim is to restore harmony within the individual and between communities. This approach takes into account the psychological and organic factors, which impacts on the individual's well-being. It is believed to be appropriate to the South African context because of its availability, accessibility, dependency and acceptability. However issues of concern relate to power dynamics, defining traditional healers, the concept of culture and generalisation within and across tribes or indigenous peoples. The following discussion will focus on indigenous knowledge and why it is important for this study.

### **African traditional healers**

Historically, African traditional healers were predominant in treating illnesses amongst the indigenous communities (Bikka, 2005). The traditional healer is defined by the World Health Organisation as:

*Someone who is recognized by the community as competent to provide healthcare by using vegetable, animal or mineral substances and certain other methods based on the social, cultural, and religious background, as well as the prevailing knowledge attitudes and beliefs regarding physical, mental and social well-being and the causation of disease and disability in the community (Oyebola, 1986:224).*

*Traditional healers are generally divided into two categories - those that serve as the role of diviner-diagnostician and those who are healers (or herbalists) (Richter, 2003:8).* The diviner is able to provide a diagnosis of an illness by spiritual means while the herbalist chooses and applies relevant remedies to those involved in healing sick people, whether the sickness is emotional, physical, social or psychosocial. Traditional healers, or *sangomas* as they are known in Southern Africa, diagnose sicknesses through the ancestral spirit and they offer traditional medicines or natural herbs. They foretell what is likely to happen in people's lives and give advice on how particular events could be avoided. Jolles and Jolles (2000) explain that traditional healers are divided into two categories: *those that serve the role of diviner-diagnosticians (or diviner-medium) and those who are healers (or herbalists). The diviner provides diagnosis through spiritual means, while the herbalists choose and apply relevant remedies. Traditional healers tend to take a 'holistic' approach to illness, treating the patient's spiritual and physical well being together (Jolles & Jolles, 2000).*

*Traditionally, Xhosa cancer patients view illness management in the Western medical setting as inadequate because no attempt is made to address the perceived cause of cancer. In contrast, a traditional healer will give instruction to receive causative hostility and will advise on the best means of restoring harmony (Hacking, Gudgeon & Lubelwana).*

Traditional healers share the same socio-cultural values as their community, including beliefs about the origins and significance of ill health. This confirms why South Africans and other African countries consult traditional healers (Gericke, 1996). Gericke further states that the approach of the traditional healers is usually a holistic one, dealing with all aspects of the patient's life, including his/her relationship with other people, with the natural environment and with supernatural forces, as well as any physical or emotional symptoms. In other words,

traditional healers provide culturally familiar ways of explaining the course and timing of ill health and its relationship to the social and supernatural worlds.

This is one reason that this study proposed to investigate the understanding of epilepsy within historically Black school in the Western Cape and to understand how they constructed this knowledge. Gilbert et al. cite Dr Ruben Sher's claim that traditional healers have an important role to play in the education system; if people in the school environment believe in traditional healers, they should be allowed to do so. Education now encourages schools to accommodate and address the diverse needs of all learners so that each individual learner receives a learning experience that 'fits' him or her based on values of mutual acceptance, respect for diversity, a sense of belonging and social justice. This statement is also emphasised in White Paper 6 (2001) where inclusive education is defined as *acknowledging and respecting differences in learners, whether due to age, gender, ethnicity, language, class, disability, HIV/AIDS or other infectious diseases* Department of Education, 2003a (Inclusive Education). Ignoring indigenous knowledge, morality and values may have affected psychosocial education adversely. Ntshangase (1995) attributes *the lack of guidance implementation in schools, in part, to the lack of sensitivity by school guidance providers with regards to alternative views of mental health and healing, for instance, traditional healing and African cultural values.*

### **2.7.2 Traditional healer's treatment of disease and illness (epilepsy)**

*Treatment consists of restoring harmony within the body, and with the environment* (Bikka, 2005). *On admission, the patient is diagnosed in a divination ritual in which bones are thrown, and through the pattern of the bones, the ancestral spirit will reveal the ailment and general condition* (Richter, 2003:15).

*African traditional medicine has a holistic view of health and treatment to health. It proposes dietary changes, herbal medication, behavioural changes and religious rituals* (Bikka, 2005). *Disease is regarded holistically, so the organic and psychological components of disease are considered simultaneously* (Sindinga, 1995).

Disease has been defined as follows:

*Not merely something from malfunctioning in this or that organ, or a lesion therein, but essentially a rupture of life harmony to be imputed either to a material cause instinct with some "intangible force" or directly to that intangible force itself. It is necessary in traditional medical practice to confront the symptomatology and aetiology of diseases not only in the material but also in the immaterial world* (Ampofo & Johnson-Romauld, 1987:40).

*Traditional healers tend to take a 'holistic' approach to illness, considering the patient's spiritual and physical well-being together, and in diseases like AIDS, epilepsy, cancer and other illness, the spiritual side becomes very important* (Steinglass as cited in Bikka, 2005). It is important to note that traditional healers and traditional medicine can vary from region to region.

The World Health Organisation proposes a broader view of health, which takes into consideration all aspects of the human being, to provide us with a holistic understanding of the concept. There has been a shift to create supportive environments, improve community actions, and provide health education and a safe environment in which people live. As Michael (1995) cited: *epilepsy should present no real obstacle to a full life, if it is completely controlled with medication*. I agree with his claim that a person can achieve a high level of confidence and self esteem if his or her epilepsy is under control by means of medication.

A child who grows up with epilepsy and is supported by his/her family and the community, feels accepted and liked, and learns at an early age to accept the condition. This, however, demands a shared vision and trust, mutual respect and a commitment from all role-players. Therefore, it is important for a child to feel loved and accepted. A good understanding of precisely what epilepsy entails by the entire system surrounding the child will reduce most of the difficulties they experience. The school has a critical role to play in understanding learners with epilepsy, as youth spend most of their time in school. The stigma associated with epilepsy can only be erased through an inclusive education system where each child feels accepted. Each learner needs to be understood within his/her context. This holistic approach is evident in the transformation currently taking place within South African's healthcare system. The Western orthodox biomedicine approach was respected and recognised by most South Africans in the past. However, it seems that its shortcomings have now made way for the alternative approaches to healing within the context being taken more seriously. It is my opinion that if Western medicine and African traditional medicine merge, this partnership could play a significant and deeply influential role in Africa's response to epilepsy.

## **2.8 AN INTEGRATED APPROACH**

While Western medicine does have an important role to play, it is recognised that the collaboration with traditional healers can increase this impact significantly (Bikka 2004). The White Paper 6 on inclusive education and training, Department of Education, 2001(Education White Paper 6) states that indigenous knowledge must be included in addressing the many



health challenges such as epilepsy, HIV and AIDS, malnutrition, unemployment and others confronting South Africa. It is with this view in mind that I believe that the traditional healers have an influential role to play in the lives of African people and evidently can make a positive contribution to comprehensive healthcare strategy. The literature suggests that the school is a viable setting to deal with these challenges (Vergnani, Fisher, Lazarus, Reddy & James, 1998). This is further supported by the White Paper 6 on inclusive education which states that all resources, including indigenous healers, should be involved in a joint venture aimed at addressing these problems. Among other things, inclusive education policy reflects human rights and social justice for all learners, equal access for all to a single inclusive education system and access for all learners to the curriculum, that have policies that reflect safe and accessible environment for the entire school community. This is envisaged to be a central strategy to address barriers to learning.

## 2.9 WHAT IS INCLUSION?

Inclusion is *a concept that incorporates a view of children with disabilities as true full time participants and members of their neighbourhood schools* (Donald & Lazarus, 1994). Inclusion is *an action or state of including or of being included within a group or structure* (New Oxford English Dictionary, 1999). Green and Engelbrecht (2001) endorse this view and describe *inclusion as the term used in education policies and practices that upholds the right of learners with disabilities to belong and learn within mainstream education*. This view is endorsed by the following definition which states that *the fundamental quality of inclusion is that all individuals of a society, regardless of sex, age, race, class or disability have the right to a quality education* Green and Engelbrecht (2001). In White Paper 6, inclusion focuses on overcoming barriers in the system that prevent it from meeting the full range of learning needs. The focus is on the adaptation of support available in the classroom.

The term *inclusion* has different meanings for individuals in different contexts. This term, therefore, is best understood within a particular national system and culture. Dyson (2001) suggests that one should rather use the term "inclusions" and speaks about varieties of inclusion. Green and Engelbrecht (2001) also see *inclusion* as meaning different things to different people in different contexts, but suggest that there are some commonalities. These include the commitment to building a more just society and equitable education system and a belief that all schools can accommodate the diverse learning needs of all learners (Dyson, 2001). The entire school system has to understand that every learner comes as a sole individual,

hence inclusive education supports and accommodates each and every learner. In practical terms this means recognising and responding to the variety of learner's needs and abilities.

Inclusion is not just about education and achievement, it also concerns respecting diversity in the educational context. It refers to the different methods and paces of learning as displayed in different individuals. Inclusive education promotes individualised teaching methods and an adapted and flexible curriculum to meet each learner's diverse needs. Inclusion acknowledges and respects the fact that all learners are different, and that the way they acquire knowledge is different. Therefore their learning needs will differ. These differences are accepted as an ordinary part of our human experiences. This implies that although learners with epilepsy might have different needs to other learners, they need to be accepted in society and be part of inclusive education.

### **2.9.1 What is Inclusive Education?**

An inclusive education system is one that acknowledges the diversity of its learner population, differences in learning styles, and differences in needs and objectives, and which is sufficiently flexible, supportive and co-operative to accommodate the diversity. It is a system that truly recognises and responds to the fact that we all have strengths and weaknesses, and might experience barriers to effective learning at times. These barriers may be caused by intrinsic difficulties such as disabilities and learning disorders.

Inclusive education also refers to an educational policy based on the principle of inclusion. This policy ensures that the system finds different ways of meeting the diversity needs as normally and inclusively as possible (Donald et al., 2002). For a school to be inclusive it must recognise and respond to the rich variety of children's needs and abilities as effectively as possible within the system (Backman & Helldin, n.d.). If the school is inclusive, learners with epilepsy will be accommodated and accepted. This is in line with the education policy of South Africa, which promotes equal opportunities for all.

### **2.9.2 History of Inclusive Education**

During the twentieth century in most countries, the education of learners with learning barriers was provided on a segregated and special basis. There were certain physical and cognitive requirements for admitting learners into mainstream schools. Inclusive education could not take place for those learners who could not measure up to the prescribed requirements and they were obliged to attend the 'special' schools. It was around 1970 that people started to challenge the policy of segregation. What started as an initiative to support

parents of children with disabilities, to campaign for the inclusion of their children in ordinary schools, developed into a far wider vision; a vision of an education system which has potential benefits for all learners?

The key to successful inclusion lies in addressing the setting of the education system to ensure that the needs of the learner are met, rather than focusing on the learner needing to fit into the system. A learner with a disability has the right to attend a school close to his or her home, in the company of his or her siblings and friends. Those same siblings and friends have the right to learn about people whose abilities are 'different' to theirs, and to accept them as part of their everyday lives.

### **2.9.3 Education in post-Apartheid South Africa**

In 1994, South Africa set an example to the rest of the world with its call for equal human rights for all citizens, with particular emphasis on recognising diversity. Inclusive education in South Africa has been promoted as an educational strategy that can contribute to a democratic society. *The movement towards inclusive education came at the right time as the new policy acknowledges diversity and disability. It also emphasises the rights of learners with disability* (Green, 2001). During the era of the new democracy, the government committed itself to the transformation of education and key policy documents and legislation stressed the principle of education as a basic human right within the Constitution. The Department of Education 2001c (Manifesto on values, education and democracy) provided a framework for systemic change in the development of inclusive education. The White Paper 6 (2001) statement does not talk about 'special' schools; it refers to the entire system. Hence the concept of inclusive education in the South African context embraces the democratic values of equality and human rights and the recognition of diversity.

The dawning of the new democracy in South Africa brought with it the challenges of reconstructing all systems of South African society. The process of change included the development of new policies with the spirit of democracy. In education, the challenge of redressing the imbalances of the past was to change the structure of the education system and change the process of education (Donald et al., 2002). These changes were framed by the Constitution of South Africa and the Bill of Rights that, among other things, emphasise the right of everyone to a basic education and *enshrine the rights of all South Africans to values of human dignity, equality and freedom* (South African Constitution, Section 29; White paper 5 on ECD, Section 3).

#### 2.9.4 History of education and special education

As a result, in 1995 the Western Cape Province decided to form the Western Cape Forum for Inclusive Education. The forum consisted of informal networks of parents and professionals (working in education in various non-government organisations) who had an interest in finding out more about inclusive education. The forum has grown rapidly into an alliance of many individuals and organisations in the province, who actively promote inclusive education as a positive model in education system, for example ELRU, Grassroots, the Western Cape Forum for Intellectual Disability, the Down Syndrome Association, Epilepsy SA, and many others. It also collaborated with the Western Cape Education Department, particularly with many of their learning support personnel, who are based at Education Management and Development Centres in District Offices.

In 1995, the South African Federal Council on Disability supported inclusive education and acknowledged that *Learners with Special Education Needs (LSEN) have a right to equal access to education at all levels in a single inclusive system that is responsive to the diverse needs of all*. The South African School Act (RSA, 1996) supported this view with section 5(1) reading as follows: *A public school must admit learners and serve their educational requirements without unfairly discriminating in any way*. It was this statement that began the enduring tension between changing the structure of education and changing the process of education that still influences progress today. *The recognition and acceptance of the basic rights of all South African children to be accommodated in inclusive school communities remains a challenge*, states Petra Engelbrecht (EJPE, Sep 2006, Vol).

During a conference on inclusion held by the Gauteng Department of Education, someone questioned whether one can expect full inclusion to take place in schools. An official representative of the Department of Education replied that "the date we are working towards is 2024" (Gous, J. Monday 07 March 2005). This kind of statement raised some questions about whether mainstream schools really do accommodate learners with learning barriers, despite the fact that since 1994 *inclusive education* has been a buzz word of the Department of Education. Professor Kader Asmal, the Minister of Education after South Africa become democratic, acknowledged that building an inclusive education and training system was not going to be easy. He emphasised to all South Africans - especially learners, teachers, parents and communities - that the implementation of inclusive education relied on their collective persistence, commitment, coordination, support and monitoring.

### **2.9.5 Inclusive education for learners with epilepsy**

Epilepsy can have an impact on learning. It must be noted that epilepsy in conjunction with the unique characteristics of each individual and their contexts may result in the barriers to learning manifesting very differently in each learner. Each case would merit individual attention and an individual support plan.

Learners with epilepsy may display one or a combination of the following difficulties:

- Memory may be seriously affected
- Poor fine-motor control, and untidy handwriting
- Problems with language and speech fluency
- Attention difficulties
- Slow to process information
- Problems with memory recall
- Problems with word recognition and recall
- May struggle to apply prior learning
- Mathematics can be affected negatively
- May experience difficulty with planning and problem solving
- Sometimes will find it difficult to communicate and interact with others

It became apparent that epilepsy is a complicated neurological condition and the learners with epilepsy will need understanding and a positive attitude from the educators and other learners. If the educators have a negative attitude towards the learners with epilepsy, this will contribute to the learner's negative attitude towards academic tasks. In accordance with inclusive education the learners with special educational needs, including learners with epilepsy, are now kept in the mainstream classroom and the educators have to take the key role as facilitators in the learning process.

#### **Support regarding learners with epilepsy**

The educators have to take the following aspects into consideration when assisting the learner with epilepsy: support during seizure, medication and their role in identifying epilepsy.

It is important for educators to provide a safe environment for learners with epilepsy in their classroom. They need to be given accurate and complete safety information if seizures, partial seizures, generalized seizures and unclassified seizures are discussed. When supporting a learner who is experiencing a seizure in a classroom, the educators have to do the following:

The educators have to remain calm and move the learner from a potentially dangerous environment. They should not restrain or hold the learner or do anything to interfere with the movements. The learner's head should be cradled if necessary or something soft must be put underneath it. It is necessary to move any hard or sharp objects away from the learner. Any tight clothing near the neck should be loosened and spectacles should be removed if the learners are wearing them. The educator should not try to stop the seizure but, if possible, the learner's head should be turned to the side to allow accumulated saliva to flow out. Nothing should be done to force the learner's mouth open or hold his/her tongue or place anything in his/her mouth. It is advisable to call medical assistance immediately if the learner's seizure lasts longer than five minutes or if the second seizure activity occurs immediately after the first seizure. This process is called 'status epilepticus'. Medical assistance will be necessary also if the learner has injured himself during seizure activity. It is important to stay with the learner until he gains consciousness because the learner will be confused and disoriented. The educator has to be supportive and comforting and she may allow the learner to rest if he still feels drowsy. If there has been a loss of bladder or bowel control during the seizure, this has to be handled with great sensitivity. If possible the learner should rejoin classmates in the regular scheduled activities. The educator has to observe the event, and describe what happened before the seizure, during the seizure and after the seizure. This information will assist the medical doctor to diagnose epilepsy and to see whether there are any precipitating factors (Krajicek et al., 1997:109; Michael, 1995:115-118; Vaughn et al., 2000:266).

### **The role of educators in identifying epilepsy**

It is important for the educators to know about the manifestation of various types of epilepsy, because they could help in the identification of epilepsy. The educators play a prominent role in identifying epilepsy. The medical practitioner will require information from various sources including educators, before epilepsy is diagnosed (Spiegel et al., 1996:34). The educators will be expected to assist the medical practitioner with the following information:

- How/what did the learner feel before the seizure? e.g. cold, hunger or tiredness.
- Any aura, warning or possible trigger factors such as pain, emotional stress or other factors.
- Was it the first seizure the learner experienced?
- What called your attention to the seizure – a cry or shout?

- What happened during the seizure and how long did it last?
- Did the seizure progress to involve other parts of the body, e.g. head turning to one side, slurred speech?
- Did the learner become stiff and fell?
- Was there shaking of any part of the body?
- What happened immediately after the seizure: symptoms such as confusion, headache, drowsiness, sleep or other responses?
- Did the learner remember anything about the seizure?
- Did the learner injure himself/herself?
- How many episodes did the learner experience?
- Information relating to possible causes, family history, history of pregnancy, birth, perinatal period, developmental milestones, previous illness and injuries.
- Information relating to current functioning in daily activities at home, school, recreational and other activities (Baddeley & Ellis, 2002:57-58; Johnson & Parkinson, 2002:16, 18; Spiegel et al., 1996:34-35).

When a seizure occurs in class, parents or guardians are to be notified and the record has to be kept. There are some learners, however, who have such frequent seizures that reposting each one to the parents becomes inappropriate. In these instances a weekly report or summary of seizure activity may be more appropriate (Bergen, 1991:18).

Record keeping of all the information about the learner with epilepsy is important. The educator is responsible for the record keeping. The management of epilepsy data should contain the date and time when seizures occurred, the type of seizure as well as its duration. The educator should indicate whether the learner took the medication on that day or not, the name of the medication as well as side effects seen in the classroom (Johnson & Parkinson, 2002:13-15; Michael, 1995:111-113).

## **Support in the classroom/environment**

In order to support the learner with epilepsy in the classroom the following aspects should be put into place: individual education plan, supportive environment, behaviour management and strategies that will reduce destructive behaviour.

### **Individual education plan**

Educators should have individualized educational plans for each learner who has a chronic condition. The individualized education plan should be prepared in consultation with parents, educators, and other school personnel including the school nurse, if available (Porter, 2002:59-60). The plan should consist of the learner's name, photo and emergency contact information. It should also include the diagnosis and description of the condition, and the individual health history including specific symptoms and level of severity. The emergency procedures should be put on the first page of the plan. Ongoing daily treatments such as health care procedures, medication administration, dosage, and possible side effects should be included in the plan. The plan should also provide the information on the additional accommodation measures taken. This includes identification of physical access and changes in instruction and activities. Example: rest breaks and changes in activity types and lengths (DePaepe et al., 2002:4; Vaughn et al., 2000:10-11).

Furthermore Ashman and Elkins (1994:19) and Janney and Snell (2000:15-17) stated that the information about current educational achievement levels and annual educational goals, including short-term instructional objectives, should be included in the plan. A statement detailing educational services to be provided and the extent to which each learner will participate in regular programmes and the appropriate objective criteria and evaluation procedures, should also be included in the plan.

### **Supportive environment**

The nature of the physical classroom environment has an effect on the behaviour and safety of both educators and learners. Educators have to maintain the physical classroom environment as safely as possible for learners with epilepsy. Educators are responsible for the learners' health and safety while they are in their classroom. Educators have to make sure that dangerous chemicals or sharp scissors are kept away from all learners, including learners with epilepsy. Educators have to put in place clear and firm strategies about dealing with bags and other equipment at the start of the lesson, a time when safety issues should be discussed (Cowley, 2003:131).



Educators need to have a blanket or other soft material to use for protection if needed. The sharp edges of classroom furniture should be covered and if possible the school management should purchase furniture with round edges. The classroom temperature should be as comfortable as possible to avoid hot or cold environments, which may hinder performance. The use of a flashlight in the classroom should be avoided as it may precipitate seizures in some learners. The use of shatterproof equipments is recommended for usage in the classroom to avoid accidents during seizure activity. The classroom environment should be barrier free and it should be arranged in such a way as to allow easy movement between desks and tables. It is necessary to make sure all learners in the classroom know first aid procedures for seizures (Lewis & Doorlag, 1995:192; Michael, 1995:122-123).

### **Teaching strategies**

Any seizure may interfere with the learner's ability to learn and if this is the case he/she may need additional assistance to keep up with the rest of the class. When educators are teaching learners with epilepsy, it is essential for the teacher to repeat the work for the learner who experienced a seizure, especially for those with memory problems. One could use the help of mentors, e.g. one of the stronger pupils in the class can help the learner who missed the lesson because of a seizure. *Considerable breaks need to be taken in between classes because learners with epilepsy get tired easily* (Kruger & Kapp, 2005). The educator can provide the learner with a tape recording of the activities done in class during his/her absence to help the learner not to feel left out of the class situation. Learners should not be exposed to dangerous apparatus in case they experience a seizure. Educators should be aware of danger signs that may prevent the learner from becoming independent and self-reliant. The educator should not be overprotective or too lenient concerning scholastic expectations and discipline. Educators also need to know how to refer a learner for learning support. Learners should be treated in the same way as their classmates and should never be categorised as disabled (Landsberg et al., 2005).

### **Behavioural strategies**

Learners with epilepsy often experience behavioural and emotional problems. They may have difficulty adjusting socially because of their disability. Educators need to assist these learners with their behavioural difficulties by maintaining a positive attitude towards them and encouraging social interaction. *The learner with epilepsy sometimes can be hyperactive, passive, confused without any apparent reason or have outbursts of moodiness. They may complain about non-existent physical aches and pains, and/or display destructiveness and*

*impulsive behaviour and be difficult to discipline* (Hopkins, 1984). The educator should create a classroom atmosphere in which the learners feel safe and loved. The opportunities should be provided for them to have a successful learning experience and the educator should use positive reinforcement to achieve this. This will create and increase self-esteem. The educator further needs to help the learners to identify and value the way in which each of them is unique. As Engelbrecht and Green (2001) state: *in order for learners living with epilepsy to be included, the school should be seen as a place where every learner belongs, is accepted, and has his or her educational needs met.*

### **Curriculum Adaptation**

Schools need to adapt their curriculum to accommodate learners with epilepsy. The curriculum should reflect those principles, such as diversity, that facilitate the education of all. The curriculum should be designed and implemented with due consideration for a wide diversity of characteristics and needs. Learners with epilepsy often experience scholastic difficulties with reading, mathematics and spelling. They have concentration problems and poor memory, they may forget to do their homework or to pass school notes on to their parents, and they may find it difficult to complete tasks. Maintaining attention and concentration can be challenging for all learners with epilepsy. This can be as a result of their medication or of the seizures themselves. A 'whole-school' approach, which is more learner-centred, should be used. The school should involve all the different systems. This includes involving the parents and the community as much as possible to create an atmosphere for the learners that's conducive to success in the schooling years. The school could consider inviting an expert on the topic to address the parents and the community about the condition. This would be one way of indicating to the learners that they are supported by the school, the family and the community to optimise their performance. The school could also organise regular meetings with parents to enlighten them on better ways of accommodating their child in the learning environment, and to raise the level of awareness within the community.

### **Teaching other learners about epilepsy**

Educators have the responsibility of helping other learners understand and accept the learner with epilepsy. The decision about when to teach the rest of the class about epilepsy should not be made by the educators alone, but it should involve both the parents and the learners. The parents have to give permission that other learners may be taught about epilepsy. The learner with epilepsy should take an active role in planning the lesson and preparations (Michael, 1995:96-97; Vaughn et al., 2000:271).

When teaching learners about epilepsy the educators have to explain that epilepsy or seizure is not a disease and is not contagious, but is a neurological condition. They also have to explain that seizure happens when the brain receives many different messages to which the body reacts, that the learner becomes unconscious, and that, after the seizure, the learner's consciousness returns to normal. When the seizure is over, however, it causes some inconvenience. Educators also have to discuss the causes of epilepsy.

The school also needs to involve the community and parents by teaching them how to handle the seizure situation. Parents and teachers can play a vital role in helping learners with epilepsy to be accepted by their peers. Educators need to assist learners with epilepsy by developing their strengths and talents through workshops and other customised activities. It is critical that the educators form a good relationship with the parents and that they communicate regularly on his/her progress.

### **Summary**

This chapter commenced by discussing epilepsy and detailed various cultural views of epilepsy. Both Western and African traditional medicines were reviewed, particularly in the context of indigenous knowledge in South Africa. Lastly inclusion, inclusive education and the support for overcoming barriers to learning linked to epilepsy were discussed.

## CHAPTER 3

# RESEARCH METHODOLOGY

### 3.1 INTRODUCTION

This chapter presents an overview of the research methodology used for this study. As mentioned in Chapter 1, the aim of the study was to investigate how epilepsy is understood within historically Black schools in the Western Cape. In this study I illustrate and justify the methods I used to try and access the understanding of epilepsy, as well as explain how I analysed and tried to verify my data and act ethically as a researcher. It explains, in detail, the research aims and questions; the research approach; the data collection method; the data analysis and research ethics.

### 3.2 RESEARCH DESIGN

One of the most important choices made in the construction of any study is the research design. Research design refers to the plan and structure of investigation used to obtain evidence to answer the research question (Kerlinger, 1986:276; Macmillan & Schumacher, 1997:33). Mouton (2001) defines research design as *a set of guidelines and instructions to be followed in addressing the research problem*. The research design I chose was positioned in the interpretive paradigm because this study wanted to understand people's subjective understandings of epilepsy in their context. In this type of research, the researcher is central to the sense that is made.

The research paradigm was developed in social science to enable researchers to study social and cultural phenomena, and is characterised as an attempt to obtain in-depth information on the topic under investigation and understanding of the meaning and descriptions of the situation as presented by the participants (Boje, 2001:4). The post-positivist ontology was used as this study focused on the factors that influence individual human beings' senses of reality and agency built on a holistic picture, formed with words, reporting detailed reviews of participants and conducted in a natural setting (Creswell, 1998). The detailed interaction makes this approach particularly appropriate to elicit adequate information from the participants in this study. In post-positivist research, the focus changes to "human constructed knowledge" with epistemology as the study of how it is constructed (Banister et al, 1994).

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*Qualitative research is seen as a set of interpretive activities which do not privilege a single methodology over another. It draws upon and utilises a diversity of approaches, methods and techniques* (Denzin & Lincoln, 2000 cited in Haris, 2004). Patton (1990) agrees with the above authors by saying that qualitative research is about finding out what people do, know and feel about observing, interviewing and analysing documents. The emphasis of my research was on understanding epilepsy within historically Black school in the Western Cape and using a qualitative interpretive approach as a process to gaining insight as to why certain things occur, rather than merely what is going on. It largely concerns the meaning which people give to their experiences, thoughts and emotions. Beukens (2002) refers to it as a creative, interactive and dynamic process that produces description and theoretical knowledge. Qualitative research deals with the familiar everyday life of the setting under study; it does not remove people from their natural setting and values the opinions of the participants.

According to Buskins the qualitative approach is characterised by:

- An orientation towards an insider's perspective.
- An emphasis on contextualization of the process of knowledge construction.
- A flexible and open research design. Validity and reliability of the research results depend to a high degree on the researcher's skill and sensitivity.
- The scope of the research tends to be on a small scale.

According to Patton (1985), *qualitative research is an effort to understand situations in their uniqueness as part of a particular context and the interaction there. This understanding is an end in itself, so that it is not attempting to predict what may happen in the future necessarily, but to understand the nature of that setting - what their lives are like, what is going on for them, what their meanings are, what their world looks like in that particular settings - and in the analysis to be able to communicate that faithfully to others who are interested in that setting.*

Qualitative research often relies on interpretive or critical social science. McMillan and Schumacher (2001:396) stated that *qualitative research is based on a constructivist philosophy that assumes reality as multilayer, interactive, and shared social experience*

*interpreted by individuals*. This means that reality is a social construction whereby individuals ascribe meaning to certain phenomena. In other words, people's perceptions are what they consider as 'real' to them and their actions, thoughts and feelings.

One of the characteristics of the qualitative approach is that it focuses on understanding the meaning people have constructed, that is, how they make sense of their world and the experiences they have in the world. It always takes place in natural settings where the researcher is regarded as the instrument of data collection. It is a systematic yet flexible process, which means that it can be adapted quite easily. Also, qualitative research usually involves field; work the researcher must physically go to people in order to observe behaviour in their natural setting. In order to construct qualitative research, certain skills such as critical analysis, obtaining trustworthy and credible data and interaction with others are required.

In summary, I used interpretive qualitative research in this study because of its exploratory nature, exploring how people understand things differently from others. Qualitative researchers assume that people act on the basis of their interpretations. My interest was their understanding of epilepsy. Their own beliefs and understanding were therefore of the utmost importance. *Qualitative researchers assume that knowledge is at least to some extent constructed rather than discovered and the researcher is to interpret meanings* (Merriam & Simpson, 1995). It is my understanding that using qualitative research means the emphasis is placed on the importance of listening to, recording and understanding participants' perceptions, which is why it was a suitable methodology to use for my study.

### **3.3 RESEARCH PARTICIPANTS**

The participants were selected by means of the purposive sampling method. This is the most important non-probability sampling (Welman, Kruger & Michell, 2005). Purposive sampling means that the sample is chosen for a specific reason and it allows the researcher to select from the spectrum s/he is interested in. Merriam (1998) mentions that *purposeful sampling* involves identifying participants, or cases of interest, from people who know people, or cases that are information-rich and that could be a good example for study, or good interview subjects.

According to Merriam (1998), *when purposive sample is applied, it is not the number of respondents that matters, but the potential of each person to contribute to the development of insight and understanding of the phenomenon that is important*. The sample chosen suits the aim of the research best.

This is why this study involved 28 participants from four historically Black primary schools in Khayelitsha in the Western Cape. I decided to choose schools that had known enrollments of learners who had epilepsy. The researcher secured permission from the authorities (Western Cape Education Department) to conduct the research. Refer to appendix 4, 5, 6 for the approval and consent letters to the principals and the participating educators, parents and learners. At each school, I interviewed five educators who, in their teaching experience, had encountered learners with epilepsy. The participants included a principal, head of department teacher, learning support teacher, junior phase and senior phase teacher. Four learners living with epilepsy were also interviewed with their parents. While the participants were representative of each school, this did not mean their perceptions were reflective of the entire school. Their participation took the form of a semi-structured interview. On the basis of the interview I continued exploring the content through literature to consolidate the literature review and fieldwork results.

### **3.4 DATA COLLECTION METHODOLOGY**

#### **Literature Review**

The literature review was guided by the following keywords: epilepsy, inclusive education, traditional, indigenous knowledge in South African context.

I used these keywords to access the relevant articles from an electronic database. I obtained the government documents from the library, particularly those dealing with inclusive education. I read international and national documents to get a clear view of current opinion on indigenous knowledge.

#### **Interviews**

In addition to the literature search, the primary data was collected through the use of interviews. According to Denzil and Lincoln (2000:645), it is believed that *interviewing is one of the most common and powerful ways in which we try to understand our fellow human beings*. Neuman (2000) agrees with the above authors, stating that the purpose of an interview is to find out what or how people feel about something. This means that by interviewing various educators, parents and learners I could determine their understanding of epilepsy.

An interview is characterised as a conversation with a goal. *Interviewing is to find out what is in, and on, someone else's mind* (Xatton, 1990 cited in Merriam, 1998). *It is face to face interaction between an interviewer and participant which seeks to build the kind of intimacy*

*that is common for mutual self disclosure*, Johnson (2002:103 cited in Henning, Van Rensburg & Smith, 2004). *Qualitative interviews may be structured or unstructured* (Mouton, 1996). For the purpose of my research I chose the semi-structured interview approach using open-ended questions to allow respondents to share their experiences in a non-threatening way. This type of interview allows the participants to provide as much information as possible, shaping questions to the position and comments of the interviewee, *without being bound by the codes of standardisation and explicability to follow an interview schedule* (Mishler, 1986 cited in Banister et al., 1994).

Semi-structured interviews provide the opportunity for the interviewer to probe and expand on the participant's responses. It offers a free flow of information between the researcher and subject. *The researcher is able to develop a rapport and empathy with those being interviewed, and once this is achieved the belief is that deeper, more meaningful information will be obtained* (Hitchcock & Hughes, 1995). Mischler cited that semi-structured interviews are an open and flexible research tool that can document perspectives not usually represented or even envisaged by the researchers. Hence this approach *can empower disadvantaged groups by validating and publicising their views* (Mishler, 1986 cited in Banister et al., 1994).

I strongly agree with Smith (1995:9) when he makes the following statement regarding the purpose of semi-structured interviews: *... to gain a detailed picture of respondents' beliefs about, or perceptions or accounts of, a particular topic.*

According to McMillan and Schumacher (2001), *this type of interview offers the possibility of freedom and flexibility to the researcher and the participant alike.*

When doing semi-structured interviews, *the researcher has a set of questions but has more opportunity to probe* (May, 1997). This gives the researcher the opportunity to probe areas of interest that the participant may raise and explore the individual's areas of concern. This interview is often more of a conversation than a formal interview.

The participants were given the opportunity to express their feelings about epilepsy. I believe that by conducting these interviews in the education environment, I achieved my goal of tapping in to educators', parents' and learners' understanding of the condition.

Anderson and Jack (1991) are of the opinion that *in qualitative research the researcher is an active participant in the collection and analysis of data.* I adhered to this principle during the interview. I tried to get as much information as possible and would ask participants to elaborate on certain answers where appropriate. (See Appendix for interview framework).



### **The development of the interview schedule**

The research instrument that I employed was an interview schedule. An interview guide is necessary to the extent that it prompts the researcher to recall the key issues to be discussed and should be more than suggestive, allowing the researcher considerable latitude to improve relevant questions and pursue unanticipated lines of enquiry as the discussion progresses (Brecwell et al., 1998). I prepared an interview schedule with open-ended questions addressing the key issues I wanted to explore. The interview schedules were developed in English and then translated into Xhosa by one of the language interpreters from the Western Cape Department of Education (see Appendix D). Before conducting the interviews I piloted the study by interviewing a learner with epilepsy together with his parents. It was easy to identify them because they were from the school which I used to work for. I asked permission from both the principal and the parents of the learner. I explained to them what the purpose of the pilot study was. I recorded the interviews that were conducted into Xhosa. The recorded discussion was transcribed by a professional person. Words were written down in the exact manner as they were said by the participants. The pilot study helped me to formulate the interview schedule according to the following:

Three separate schedules were developed, one for educators, parents and learners respectively. The questions focused on their depth of understanding of epilepsy. According to Cohen and Manion (1998), *the importance of preparing an interview schedule should not be underestimated because by preparing an interview schedule it forces you to think about what you think or hope the interview might cover*. It gives you time to think of the difficulties that might be encountered, for example, in terms of question wording or sensitive areas, and to give some thought to how these difficulties might be handled.

The experience gained from the pilot study enabled me to know that, when doing interviews with participants, I should have notes taken during the process. Morse (1994) describes these field notes as a written account of the things the researcher hears, sees, experiences and thinks in the course of collecting or reflecting on the data obtained during the study. In notes taken I noted the order in which people speak, on verbal behaviour such as eye contact, fidgeting etc, themes that are striking, and highlighted as much conversation as possible (De Vos et al., 2002). It is important that this be done as soon as possible after the focus group session. The breadth of the subject matter for diary or field records is as big as the imagination of the researcher (Breakwell et al., 1998).

In my case I recorded thoughts and feelings as well as accounts of physical social context in diary format. This was done directly after each and every interview discussion, as well as during the week, when certain thoughts and memories of the people and conversation struck me as significant. I thus had two sources of data: written scripts and field notes. I used my diary and field notes to support me in analysing the data and to clarify interpretations made from discussions. It also helped to identify key themes and opinions as well as some of the possible concerns of the educators, parents and learners that were not communicated directly.

I noted my reflections immediately after each interview because reflections often capture more insights from the interview. These reflections included descriptive notes on verbal and nonverbal behaviour of the participants. Merriam (1998) argues that *post-interview notes allow the investigator to monitor the process of data collection as well as to begin to analyse the information itself*. Some of the advantages of this type of interview are that the interviewer is more free to probe interesting areas that arise. It also gives the interviewer the opportunity to explore the participants' interests and concerns. Because of this greater flexibility, it produces richer data. *The written word is the basic medium for analysis* (Katzenellenbogen, Joubert & Abdool Karim, 1997; Merriam, 1998). Where the participants agreed, interviews were tape recorded and subsequently transcribed. Fifteen educators preferred detailed note taking. Five educators preferred to give written feedback and insisted that I leave the questions with them. This feedback was incorporated into the analysis.

### 3.5 DATA ANALYSIS TECHNIQUES

A content analysis was used in this study. Content analysis is a research approach used to determine the presence of certain words or concepts within a text or sets of text. *This method helps the researchers to qualify and analyse the presence, meanings and relations of such words and concepts, and then make inferences. This means that data is coded under common themes and then compiled into categories. Later these codes become the basis for further analysis* (Krippendorff, 1980).

The data was analysed in terms of six research sub-questions. I used thematic analysis as a strategy to analyse the data (see the example of an analysed interview in the appendix). According to Banister, Burman, Pookes, Taylor and Tindall (1994:57) a thematic analysis can be described as a *coherent way of organising some interview material in relation to specific research questions*.

I read through all the data obtained during the interviews and organised it under thematic headings as per the research questions. I first considered each extract separately and then moved on to *elaborate connections and contrasts between them in relation to the themes* (Neuman, 2000). As I did this, I revisited my reflections on each interview to tie in to the themes that emerged while categorising the data. I included non-verbal expressions as observed during interviews, since these cues contained subtle nuances of meaning that were crucial to the overall interpretation of the data. From this, I recorded my interpretation of the grouped themes under similarities and differences. The act of constant comparison ensured that my analysis was consistent and that no data was unassigned. By employing qualitative analysis an attempt was made to capture the richness of the themes emerging from the interview as recommended by Denzin and Lincoln (2000). I was active in the process of identifying themes and it thus represented my perceptions. An example of a transcript is included as Appendix D.

### 3.6 RELIABILITY AND VALIDITY

*Reliability refers to the accuracy of the actual measurement or procedure. Validity in qualitative research means the degree to which the interpretations and concepts have mutual meaning between the participant and the researcher* (McMillan & Schumacher, 2001). This is considered an indication that the instrument has measured what it was supposed to measure. Ensuring that data is accurate is an important principle in research. I developed an interview schedule that was checked by my supervisor for reliability and validity. Furthermore, the validity of the interviews was maintained by means of rephrasing and confirmation.

I made sure that I understood what the participants were saying by asking them to confirm that what I had interpreted was what they meant. This is called verification of the data. It is important for the researcher and the participant to have mutual understanding of what is being said. In addition random interview transcripts were checked with participants. After some of the interviews with educators, I went back to check if my interpretation of the data was correct. The presence of a co-researcher enabled further checking of understanding.

According to Merriam and Simpson (1995) *external validity does not refer to the extent to which one finding can be generalised to other situations, but to the extent to which findings from an investigation can be applied to other situations*. The sample of schools was specifically chosen to represent different school contexts in the Western Cape and can facilitate what Stake (1995) refers to as *naturalistic generalisation*.

### 3.7 RESEARCH ETHICS

Banister, Burman, Parker and Tidall (1994) mention that *it is important to disclose satisfactory information on the purpose of research in order to allocate ourselves firmly within both the research and the participant's world, hence ensuring interpersonal connection*. This allows participants to understand the position of research. I made appointments with all the participants to fully explain (in the language of their preference) my intentions with this research. Educator and parents were given a consent letter to sign and learners assent letters giving their permission to conduct the study. Furthermore, every participant was told that they need not answer all the questions or continue talking about an issue that was uncomfortable for them.

The interviews took place in a variety of settings including offices, classrooms and staff rooms. A co-researcher attended all the interviews to help ensure the accuracy of the data. I emphasised repeatedly that the purpose of this interview was to explore how the participant understands epilepsy and that there were no right or wrong answers. It was important that each individual felt they could trust me for an open and trustworthy interview. The research contract included guarantees such as anonymity and confidentiality. Reiss (1979:73) makes the following statement to emphasise the importance of privacy and confidentiality: *The single most likely source of harm in social science inquiry is the disclosure of private knowledge considered damaging by experimental subjects*.

Participants were guaranteed that no information would be linked to particular individuals, thus exposing their identity. In reporting the data, I took care not to include information that would identify schools or individuals. The participants were coded according to whether they were learners, parents or educators. Participants were given feedback and each participating school has been provided with a summary of the research findings.

### **3.8 SUMMARY AND CONCLUSION**

This chapter outlined the rationale for the research approach and described the processes of data collection and analysis. Chapter 4 will present the research findings and limitations of this study. The qualitative approach to research, where the participants agreed, interviews were tape recorded and subsequently transcribed, was used. Fifteen educators preferred detailed note taking while five educators preferred to give written feedback and insisted that I leave the questions with them. This feedback was incorporated into the analysis, which also allowed me to obtain in-depth information on the topic under investigation. The detailed interaction makes this approach particular appropriate to elicit adequate information from the participants in this study.

## CHAPTER 4

### PRESENTATIONS OF FINDINGS

#### 4.1 INTRODUCTION

This chapter presents and discusses the analysis of the data collected. The analysis process that was engaged was covered in chapter Three. The findings are presented in terms of the research sub-questions. The themes that emerged from the analysis of the interviews are presented and illustrated by chosen quotations, within a framework. Where sub-themes were identified, these are also indicated. Data are presented in the narrative manner. The data were analysed according to content analysis described in chapter three. The following emerged.

#### 4.2 EDUCATOR, PARENT AND LEARNER UNDERSTANDING OF EPILEPSY WITHIN HISTORICALLY BLACK SCHOOLS IN THE WESTERN CAPE

**The educator's understanding is organised under the following themes:**

- Knowledge about epilepsy
- Reactions of educators towards learners with epilepsy
- Effect of epilepsy on learning
- Inclusion in regular class
- The need for epilepsy policy in schools and need for curriculum change

Knowledge about epilepsy proved not to be the same and consistent amongst educators. Some educators knew what epilepsy entails; most did not fully understand the concept of epilepsy.

##### 4.2.1 Knowledge about epilepsy

###### **Accurate knowledge:**

*E4: It is caused by chemical imbalances in the brain and is like an electrical activity in the brain.*

*E12: An injury to the brain that causes one to experience convulsions.*

###### **Inaccurate knowledge:**

*E2: When the child has a fit, clothes should be taken off so that the child feels free.*

*E18: When a child gets a 'fit' I know I need to put something in the child's mouth to prevent the child from biting his/her teeth.*

Certain myths concerning epilepsy still exist among educators. What was particularly interesting for me was the fact that most had no knowledge of epilepsy and were unsure how to handle a learner with epilepsy in the classroom situation. This means that a learner experiencing an absence seizure in class would not get the necessary support from the educator. Often these learners are merely labelled as 'lazy'.

*E20: Is when the child is possessed by evil spirits (amafufunyana) and is bewitched, the child will get fits?*

#### **4.2.2 Reactions of educators towards learners with epilepsy**

The majority of educators believed that their school culture displays feelings of compassion, understanding and commitment. Most educators felt that the staff would react positively towards learners with epilepsy. Most educators emphasised how their school fosters a loving inclusive atmosphere, yet I often found myself wondering whether this was true or whether they were merely trying to create a good impression. It was interesting to note that, although educators strongly believe in inclusive education, some believed that learners with epilepsy should be segregated and placed in one school where educators will be specifically trained and equipped to teach them.

##### **Positive Reactions**

*E7: The teacher tries their best to assist the learner who experiences the episode at school.*

*E13: The staff is very understanding and have unconditional love for every learner here at school.*

*E19: Our staffs are committed to helping any learner.*

##### **Negative Reactions**

*E4: The staff are not trained how to handle learners with epilepsy – and how does the Department expect educators to perform this duty as well with such a load of work.*

*E8: These learners will disturb the class; if they don't want to do any activity they start to have fits. Hence other teachers don't accept these learners because at times they are very manipulative.*

*E10: There are those on the staff who do not have any compassion towards children with epilepsy.*

#### **4.2.3 Effect of epilepsy on learning**

The quotations illustrated that the majority of educators were concerned that the learners with epilepsy would not be socially accepted by their peers. Only a few educators felt that the other learners in the class fully accept the child with epilepsy.

##### **Frightened:**

*E12: Other learners laugh and tease the learner with epilepsy; they run away when witnessing an 'attack'.*

*E16: Learners are afraid and do not know what to do if the learner gets a seizure.*

*E18: Learners are normally scared and frightened when witnessing an 'attack'.*

##### **Teasing:**

*E4: Other learners laugh and tease the learner with epilepsy.*

*E10: The children will laugh and tease the child with epilepsy*

The time used to attend to the learner experiencing an attack can take time away from overseeing other learners and they may resent this.

*E2: There are learners with epilepsy in our school, they are in usual classes and learn and participate like any other learners, but if one of them has an attack I have to attend on him and leave other learners unattended.*

In some cases the learner might underachieve in class because the educator does not understand his or her condition and therefore is not using the most effective teaching strategy.

*E4: The learner who has epilepsy in my class struggles with reading and maths and she attends a learning support class.*

#### **4.2.4 Inclusion in regular class**

Educators were worried about how inclusion will fit with learners; not only are they afraid of the learner with epilepsy but they could even make fun of the sufferer's situation. As mentioned in Chapter Two, the process of inclusion requires change. Change is not a simple process. It brings out feelings such as anger, resentment and resistance. Muthukrishna



(2001:50) shares this sentiment in the following statement: *It is a complex process that involves attitudes, action, beliefs and behaviors.*

A handful of educators felt that the other learners in the class would accept the learner with epilepsy.

*E13: Most children do sympathise with learners with epilepsy.*

*E17: Other learners do understand that it's not their fault - they have been bewitched.*

The literature also reveals that some educators perceive the movement towards inclusion as threatening, and therefore it is expected that inclusion will meet with a great deal of covert resistance from both educators and learners.

#### **4.2.5 The need for school guidelines**

According to the educators interviewed none of their schools had any guidelines in place for the inclusion of learners with epilepsy. Some of the participants revealed that they did not know what was expected of them, or how they should treat learners with epilepsy. I got the impression that most educators regard the setting of guidelines as something that needs to be done by the school management team. Not one educator had asked for guidelines regarding the inclusion of learners with epilepsy. Clearly, none of them understood that, as an educator, they have a responsibility for formulating guidelines.

*E5: We do not have guidelines regarding learners with epilepsy.*

*E8: I have never heard of epilepsy policy in this school.*

*E9: In this school we have a number of learners with epilepsy. If the learner has an attack we just phone the parents because we had no guidelines or epilepsy policy.*

#### **4.2.6 The need for curriculum change**

Educators were of the opinion that the curriculum needs to be revised since it is not addressing the issues dominating the context of their community. They believe that if epilepsy formed part of the curriculum, learners and educators would have an opportunity to learn more about epilepsy. This would make the inclusion of learners with epilepsy easier.

*E12: Learners with epilepsy experience concentration and behavioural difficulties, learners with epilepsy have barriers to learning. The curriculum has to be taken into consideration.*

*E 15: I think having epilepsy as part of the curriculum can create an awareness.*

*E17: I would like to see barriers to learning like epilepsy and other disabilities included in the curriculum. The department is only focusing on HIV and AIDS.*

*E18: The National Curriculum Statement should include epilepsy or all disabilities in one of the learning areas e.g. in Life Orientation - they are only focusing on incurable diseases. If epilepsy is a part of our curriculum it means that I can teach learners and they get the opportunity to learn about epilepsy.*

#### **4.2.7 Teacher education support**

The educator's understanding needs to be more effective in supporting learners with epilepsy. Not only was support within the education system identified by educators, but they emphasised the need for support beyond the education system such as non-government organisations. One educator highlighted the need to address learning barriers with a holistic approach that includes the cultural and the spiritual aspects of the individual by involving the support of traditional healers. The educator mentioned that traditional healers can play a significant role - they can teach the schools about the holistic approach they use in their practice as well as the beliefs systems of the community, and advocate that traditional healing should be taken into consideration in schools. The National Curriculum statement highlights the significance of culture and spirituality in the learning and development of individuals, particularly young learners. Brady (1997) emphasises that *education should respect the right of indigenous people to culturally inclusive curricula.*

*E2: We need workshops on epilepsy and how to address the needs of learners.*

*E7: Educators can only deal with learners with epilepsy if they are trained to do so.*

*E10: If the Western Cape Education Department wants us to implement inclusion it is their duty to give us adequate support.*

*E14: Medical resources and traditional healers should be merge because some of us strongly believe in traditional healers as well as western doctors. This can be a very essential pillar of support especially when educating learners with a medical condition such as epilepsy.*

### 4.3 LEARNERS UNDERSTANDING OF EPILEPSY

#### 4.3.1 Learner's knowledge of epilepsy

According to the responses from the learners, most were not fully aware of what epilepsy is. This means that there is a need to educate learners about epilepsy. Learners, parents and educators all need workshops to gain knowledge and skills to cope with the learner with epilepsy.

##### **Accurate knowledge:**

*L3: I was told at hospital that I have an injury of the brain.*

##### **Inaccurate Knowledge**

*L1: Epilepsy is when I get fits my head spins and my body will start jerking for 20 minutes.*

*L2: If I get fits I need someone to take off all my clothes so that I am not tight - my body should be free.*

*L3: I was bewitched by the black magic and this has caused when I am sick I bite my tongue and my body will start jerking.*

#### 4.3.2 Reactions of other learners towards the learners with epilepsy

##### **Positive Reactions**

*L1: Other learners are aware of my condition and they help me.*

*L2: I have told my friends that I have fits and they have accepted me.*

*L4: My classmates they know when I am having fits I will need to sleep.*

##### **Negative Reactions**

*L1: It's embarrassing to have fits in front of other learners, hence other learner tease me.*

*L2: Sometimes other learners will tease me about my situation.*

*L3: When I am having fits other learners think that there is something wrong with my mind they will call me names.*

*L4: I am experiencing concentration difficulties, I forget very easily and I'm very shy in class.*

Once again the ignorance about epilepsy comes to the fore. Most of the learners interviewed mentioned social alienation from their peers. It might happen that it is due in part to their

peers' lack of understanding of epilepsy. Learner understanding of epilepsy is clearly limited. This was proven by the study conducted in the United States by Austin et al. The study reported that 52% of teenagers surveyed had never heard of the term *epilepsy* and 26% were unsure if epilepsy was contagious. The study also reported that learners with epilepsy experienced fear, increased anxiety and embarrassment due to their seizures. The learners mentioned missing social events and school due to their attacks and the need for medical appointments.

#### **4.4 PARENTS UNDERSTANDING OF EPILEPSY**

##### **4.4.1 Parents' knowledge of epilepsy**

**Accurate knowledge:** No accurate response was given by parent participants

**Inaccurate answers:**

*P1: Something wrong in my child's brain that makes him to have low IQ.*

*P2: Is when my child's body jerking for about 1 minute.*

*P3: Epilepsy in my child was caused by a car accident that he was involved in.*

*P4: Is the evil spirit that is possessing my child (amafufuyana).*

**Parents' negative feelings**

*P1: My child's situation sometimes embarrasses me because when we are in church he will have the 'attacks' in front of congregation although I'm being told that he cannot control himself.*

*P2: Sometimes when my child gets a fit in public I get shy.*

*P3: It is a burden to have a child with epilepsy.*

*P4: My child is most troubled with concentration difficulties. She cannot focus and she is very impatient and irritable.*

**Parents' Positive Feelings**

*P2: I accept my child's condition and I am giving my child all the love that she needs.*

*P3: I know my child is my responsibility I have to take care of him hence I never sit down and look that my child is dying I went to traditional healer for help.*

*P4: I give my child all the love and care she deserve.*

#### **4.4.2 Reactions of community towards the learners with epilepsy**

##### **Role of traditions**

*P1: People in the community they call my child by names, such as nuts and mad. People in the community have a belief that certain traditions and values are entwined.*

*P2: Some of my neighbours asked me if my child is bee cursed and they advised me that the child needs to be healed by various types of herbal medication.*

*P4: My child is regarded as an outcast in the family; she is not allowed to play with others because her illness is contagious.*

##### **Rejection**

*P3: People in the community tend to exclude children with epilepsy from all activities.*

*P4: Children with epilepsy are not a priority in the community - they are just being ignored.*

##### **Acceptance**

*P2: In my community they have accepted my child and they offer their help if I am in need of any.*

#### **4.4.3 Medication used for epilepsy**

*P1: My child is using herbs which I got from the traditional healer and Epilim that she normally gets from clinic.*

*P2: My child is not taking any treatment only using herbs which I got from traditional healers.*

*P3: My child is using Carbamazepine and, folic acid.*

According to the statements made by the parents, they did not really understand what epilepsy entails. However, they all acknowledged that their children are struggling at school and that epilepsy does play a role in their children's performances. The parents were of the opinion that the community still perceives a child with epilepsy as an outcast and that the child is essentially rejected by the community. Some communities believe a curse has been imposed on the child. Once again, these quotations illustrate the continued existence of myths concerning epilepsy. This is an indication that people in the communities are not well informed about epilepsy. It is interesting to note that in black communities, certain traditions

and values are still entwined with epilepsy. Some parents firmly believe that only traditional healing and herbal medication can help the child.

The literature indicates that almost 80% of South Africans consult traditional healers and use traditional medicine (WHO, 2002). This includes educators, parents and learners.

Julek (1994) suggested that parents consult a traditional healer when their children have a problem such as substance abuse. This therapeutic approach was based on the fact that indigenous culture and religions have been found to be generally as effective as, and in some cases more successful than, official treatment in the rehabilitation and presentation of chemical substance dependence in Asia, the United States of America and southern Africa. This point supports why traditional healers are being consulted by educators, parents and learners. Brown (2001) cited that in some countries, traditional healing approaches are the main resource used to address various problems relating to health and wellbeing, while in other countries, including many 'western' societies, traditional healers and 'western' medical practitioners are often consulted simultaneously. Jolle and Jolles (2000) write that traditional healers *tend to take a 'holistic' approach to illnesses, treating the patient's spiritual and physical wellness together. With terminal diseases like AIDS, the spiritual side becomes very important.*

It is evident that traditional healers can play, and are already playing, a vital role in addressing the issue of HIV and AIDS. The government is beginning to realise the importance of traditional healing in the country and has passed a Bill on Traditional Healers Practitioners through which the traditional healing system will be regulated (Government Gazette, 2003). In the Cape Times of September 2004, the Minister of Health, Manto Tshabalala-Msimang said that the Department of Health had taken the first steps in recognising traditional cures for HIV and AIDS. It seems therefore that there is a move to include traditional healers in the formal health system. The Minister of Health went on to say that the government would take care of the education and training needs of traditional healers and protect the country's indigenous knowledge. One educator mentioned that if traditional healers and western doctors can collaborate and disclose the way they each view health, they could reach consensus on how to blend the two systems in addressing health challenges. The two health systems speak to the same issue from different perspective.

## **4.5 CONCLUSION**

This chapter has represented the data gathered during the interviews with educators, parents and learners on their understanding of epilepsy within historically Black schools in the Western Cape. The main points that emerged were the lack of information about epilepsy among educators, parents, learners and the broader community. Other key issues included: a variety of attitudes, the desire for information and skills regarding epilepsy, the urgent need for clear guidelines, the need for curriculum change, the desire for support and the need for community involvement. It appears from the responses that people do consult traditional healers for the different challenges they experience in life and that some people use the traditional healing system together with the western system. It appears that the way forward is in incorporating traditional healers in the formal system of education so that their knowledge can be channelled towards supporting education for the effective learning of children and improved teaching by educators.

In the next chapter I will reflect further on the findings of the study. Thereafter the limitation of this study will be briefly discussed, followed by recommendations for further actions.

## **CHAPTER 5**

# **DISCUSSIONS AND RECOMMENDATIONS**

### **5.1 INTRODUCTION**

The study focused on understanding epilepsy within historically Black schools in the Western Cape. From in-depth interviews with the participants of this study, the main findings indicate that there is a lack of information about epilepsy among educators, parents and learners. There are a variety of attitudes and actions needed, including the desire for information regarding skills and clear guidance, the desire for curriculum change, the need for support and the desire for community involvement. Furthermore, this study indicated that educators, parents and learners in the community of Khayelitsha in Western Cape do consult traditional healers for various health reasons to ensure their wellbeing. This chapter will summarise the findings from the data analysis presented in Chapter Four.

### **5.2 DISCUSSIONS OF FINDINGS**

Most of the educators had limited, or no, understanding of epilepsy. This played a major role in determining their stance towards the inclusion of learners with epilepsy. All the educators in this study realised that they need to get information and skills regarding epilepsy and they expressed the need for such training. The social and academic concerns regarding the inclusion of learners were also a major issue. Educators were worried about the impact the child with epilepsy has on the other learners in the class. None of the educators had any guidelines available at schools concerning how to deal with learners with epilepsy. This caused much frustration for educators when working with these learners.

Forli, Douglass and Hattie (1996) mentioned that educators have a responsibility to cater for the needs of all children in their classes. Their belief regarding acceptance of inclusive education may affect the degree to which they carry out that responsibility. The context in which the schools are situated also affects the schools. The school needs to understand the culture of their learners as this is vital to education support services. It is my opinion that holistic, culture and spiritual issues should not be treated as separate and distant entities from the learner.



### 5.3 LINKS TO PREVIOUS RESEARCH FINDINGS

#### **Wide range of understanding, attitudes and misconceptions**

Although some educators, parents and learners appeared to understand, most participants in this study had no idea of what epilepsy entails. Their beliefs about epilepsy were often the result of inaccurate information. As a result, some educators felt strongly about not having a learner with epilepsy in their class because of the impact on the other learners. This played a vital role in determining their understanding regarding epilepsy. I am of the opinion that their social concerns are due to a lack of knowledge of epilepsy. A vast majority of educators did not know what epilepsy entails and mentioned concerns such as "it would not be good for the environment". I agree that witnessing a learner having a seizure can be frightening, but I am sure that if learners are exposed to it more often, they will get used to it. I also feel quite confident that educators underestimate the knowledge of the other learners regarding epilepsy. My experience proved to me that it is often the other learners who step in and help the learner experiencing an attack.

I agree with Devinsky (1994) who states that we need to understand what epilepsy entails in order to erase all the myths. Gordon and McKinley (1986) noted that learners with uncomplicated epilepsy should attend mainstream school. Some of the educators felt that the severity of the seizures would determine their willingness to include a child with epilepsy in their class. This is consistent with a study done by Forlin, Douglas and Hattie (1996) which showed that inclusion becomes less acceptable, the higher the degree or severity of the disability.

In this study, most educators were not entirely open to the inclusion of learners with epilepsy. Studies by Harris (1998) in South Africa, and Barnett and Kabzemes (1992) in Zimbabwe, agree with this finding and state that the majority of educators had a negative attitude toward inclusion. This is in direct contrast to a study done by Davies (1995) in South Africa, who found educators to have positive attitudes towards inclusion. It should be noted, however, that this study was limited to the inclusion of learners with low to medium levels of special educational needs, and it did not include epilepsy. In South Africa, the policy of education claims that every citizen has the right to education and through South Africa Schools' Act (SASA, 1996) with the establishment of School Governing Body (SGBs), the intention was to allow educators and parents to take control of the education of their children. The White Paper 6 also emphasises a community-based approach to facilitate effective education. The implementation of policy presents challenges, and unless these challenges are addressed

through training efforts that are linked to other agencies such as non government organisation that offer services in the community, the policy will remain theoretical at best.

#### **5.4 THE NEED FOR TRAINING AND SUPPORT**

All the educators included in this study emphasised the need for training. This finding supports a study done by Johnson and Thomas (1999) that reported staff development as vital in the success of inclusion. Tonelson and Appolone (1981) concluded that workshops on epilepsy would restore the educators' confidence when working with learners with epilepsy. This is also the opinion of Brannon, Wilding and Jones (1992) that carried out a study which found that educators would only gain confidence in their ability to work with learners with epilepsy through experience and training.

The educators in this study acknowledged the need for support and stated that currently no support is available for parents and learners with epilepsy within their schools. Most of them were of the opinion that the Department of Education is implementing policies without providing adequate support to execute these policies. A study carried out by Harris (1998) supported this argument. However, the study done by Davies (1995) found that 57% of the participants indicated that they did not require any form of support. Davies' work did not, however, refer to epilepsy specifically, but included learners with low to medium special educational needs.

#### **5.5 THE NEED FOR COMMUNITY INVOLVEMENT**

Most educators and parents felt that there was a definite need for the school to work systematically. Lazarus, Daniels and Engelbrecht (1999:56) cited in Engelbrecht, Green, Naicker and Engelbrecht share this concern and support it by making the following statement: *The benefit of parent involvement in the development of an inclusive school is not only beneficial to the school. Having a close partnership with parents enables parents to further develop their own skills and understanding in supporting their own children through the schooling process. The development of an inclusive school has to be placed in the context of building an inclusive society of which the family is a central part. The values and norms of the school that reflect the principles of inclusion need to be developed within the family and other parts of community life.*

This statement mirrors findings by Bannon, Wildig and Jones (1992) and Sergiovanni and Starratt (1998) who found that a lack of proper communication between parents, medical staff

and teachers could affect the learner with epilepsy negatively. Another study carried out by Scott (1973) also emphasised the importance of collaboration for learners with epilepsy.

## **5.6 THE NEED FOR MEDICAL TREATMENT**

The findings of the study indicated that educators, parents and learners do consult traditional healers for epilepsy. It appears that this consultation of traditional healers occurs on an individual basis because people do not want to be seen with traditional healers due to the historical stigma associated with such healers in the society. The knowledge of traditional healers was marginalised by the apartheid government and so it was practised secretly. In those days some traditional healers were arrested for practising this indigenous knowledge. Other parents mentioned that they use hospital treatment together with herbal treatment and it worked well for their children.

## **5.7 RECOMMENDATIONS**

On the basis of this small scale, exploratory research, I can now make the following recommendations regarding the understanding of epilepsy within the historically Black schools in the Western Cape.

Misunderstandings concerning epilepsy still exist. Most of the participants did not have a problem accommodating learners with epilepsy in their class although those that did, did so because they did not know how to support them. Some of the participants mentioned that they did not know how to identify a child with epilepsy.

Although most educators felt that it was the Western Cape Education Department's duty to provide workshops, I do feel that schools should also initiate their own workshops. They could make use of non-governmental organisations such as Epilepsy South Africa to assist them in structuring and presenting their workshops as well as to empower the parents, learners and community about epilepsy.

Information workshops regarding epilepsy should be a priority. Workshops should be given to inform educators, parents and learners about epilepsy. The role of in-service training cannot be underestimated. There is a definite need for this regarding learners with epilepsy. Educators would feel much more confident handling a child with epilepsy once they know about the condition.

There is an urgent need to develop and formulate guidelines with all role-players. It is recommended that a comprehensive, clear and implementable policy should be formulated by the schools themselves in collaboration with the Department of Education.

Some of the educators in this study stated that they were aware of the fact that they cannot exclude children with epilepsy from their school. However, they wanted policies regarding medication, absenteeism, management of seizures etc. for learners with epilepsy. The school could have a curriculum adaptation regarding learners with epilepsy.

#### **5.7.1 Schools to identify and have some source of support**

The majority of participants acknowledged the need for support services. They wanted support services in place in the form of remedial support such as linking mainstream schools to special schools where there are structures of support, specialist assistance, medical assistance etc. This could begin with the merging of the knowledge and skills of traditional healers and Western doctors to create the platform to train educators and promote the awareness of epilepsy. This collaboration of traditional healers and Western doctors should be tailored towards addressing barriers to learning and development.

#### **5.7.2 Engage the community**

Perceptions towards children with learning barriers associated with epilepsy have often been influenced by misinformation and/or lack of information. Prejudices, myths and misunderstandings continue to affect the learner with epilepsy. The comments of some of the educators and parents revealed that they had a negative attitude towards the child with epilepsy. They were worried about the effect of the child with epilepsy on the rest of the class and community. They seem to regard this child as an outcast who would affect the rest of society in a negative manner. Epilepsy South Africa has to play a role of minimising the negativity of epilepsy within the community of historically Black schools in Western Cape.

These perceptions would definitely cascade down to the learners with epilepsy. It would only be changed if educators and parents accept responsibility for helping themselves and others to understand and accept the child with epilepsy (Svoboda, 1979).

Parents remain one of the most potentially valuable resources in education and not to mine this largely untapped resource would need a great deal of justification. It is generally accepted that when educators and parents work together in partnership, the education of their children improves.

## 5.8 SUGGESTIONS FOR FURTHER RESEARCH

1. A study should be carried out to find out what traditional healers think they can contribute to support learners with epilepsy in schools.
2. Further studies should be done to establish how many unidentified learners with epilepsy are currently in mainstream schools. The fact that many children with epilepsy are not identified could lead to disastrous consequences.

## 5.9 LIMITATION OF THIS RESEARCH

This research was conducted in one province which makes it difficult to generalise its findings to other parts of the country, and the restricted number of participants adds to this difficulty.

This was a qualitative study and the sample of educators was not randomly selected. This means that the findings are not generalisable to all educators. However, this sample of schools was chosen to present different school contexts in the Western Cape and can facilitate what Stake (1995) refers to as naturalistic generalization.

These interviews took place just before schools closed and I often got the impression that educators were tired and not really focused. A problem I experienced with these interviews was that it took longer to carry out and participants often spoke of issues that were not related to the purpose of the interview. Unfortunately, one of the disadvantages of this type of interview is that it reduces the control that the interviewer has over the situation (Cohen & Manion, 1998).

## 5.10 CONCLUSION

In conclusion, Brown (1993:98), as cited in Schofield-King (1995), briefly summarises the present situation but gives us hope for the future!

*Because of the lack of understanding among educationalists of special issues involved even when the school knows the child's epilepsy, children with epilepsy are at risk of underachieving at school. However, good practice today will have beneficial consequences for tomorrow's adults' provision.*

This study has illustrated the scope of understanding of epilepsy within historically Black schools in Western Cape. The major implications are the need for information and skills regarding epilepsy, the need for clear guidelines, the need for support services and the need

for community involvement. These form the basis of the recommendations. An epilepsy management programme focused on the awareness of epilepsy can emphasise health education in that it will allow educators, parents and learners with epilepsy to manage their own condition and allow a greater degree of autonomy as they become young adults. The schools need to take the culture of learners into consideration. Culture plays a role in the context of education. From the above discussion it is clear that many have strong faith in traditional healers. *If schools can collaborate traditional healers with medical doctors to provide a support to the centre of learning, with special focus on the inclusion and utilisation of community resource in defining that support* (Lomofsky & Lazarus, 2001). Furthermore, *the interdependence of expertise has to be taken into account* (Department of Education, 1997). As an outflow and outcome of this study the researcher plans to develop the guidelines on the management and support for learners with epilepsy which can help parents and educators in supporting these learners.

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**APPENDIX A:**  
**INTERVIEW SCHEDULE FOR EDUCATORS**

**UMGAQO WODLIWANO NDLEBE  
INTERVIEW SCHEDULES  
WABA FUNDISI NTSAPHO  
FOR TEACHERS**

**UKUQONDA NGESIFO SOKUWA /UKUXHUZULAKWIZIKOLO EZINEMBALI  
ZABAMNYAMAKWI PHONDO LWE NTSHOANA KOLONI  
UNDERSTANDING OF EPILEPSY WITHIN HISTORICALLY BLACK SCHOOL  
IN THE WESTERN CAPE**

Inkcukakca ngomthabathi nxaxeba

*Details of participants*

Igama : .....

*Name:*

Iminyaka mingaphi:.....

*Age*

Ibanga eliphezulo lwezifundo:.....

*Highest qualification*

1. Wazi ntoni ngesifo sokuwa okanye sokuxhuzula?

*What do you know about epilepsy?*

2. Ulufumene phi olu lwazi unalo ngesifo sokuwa okanye sokuxhuzula?

*How did you obtain this knowledge about epilepsy?*

2.1 Ezincwadini *Books?*

2.2 Ngamava *Experience?*

2.3 Kuqeqesho *Training?*

3. Ingaba ikho into eyenziwayo esikolweni malunga nabafundi abanesifo sokuwa okanye sokuxhuzulayo ?

*What happens at this school regarding learners with epilepsy?*

4. Abafundisi ntsapho kwakunye nabafundi babathatha njani abafundi abanesifo sokuwa okanye sokuxhuzulayo ?

*How educators do reacts towards learners with epilepsy?*

5. Zithini izimvo zakho malunga nokufundisa abantwana abasifo sokuwa/sokuxhuzula esikolweni?

*What is your perception as educators about inclusion of learners with epilepsy?*

6. Loluphi ukhuselo olwenziwa sisikolo malunga nabafundi abanesifo sokuwa/sokuxhuzula?

*What intervention does the school provide for learners with epilepsy?*

7. Ingaba ikho enye into ocinga ingalucedo onokundixelela yona?

*Is there anything else that you think would be useful for me to know?*

**APPENDIX B:**  
**INTERVIEW SCHEDULE FOR PARENTS**

## UMGAQO WODLIWANO NDLEBE

### INTERVIEW SCHEDULES

#### WABAZALI

#### FOR PARENTS

### UKUQONDA NGESIFO SOKUWA /UKUXHUZULAKWIZIKOLO EZINEMBALI

### ZABAMNYAMAKWI PHONDO LWE NTSHOANA KOLONI

### UNDERSTANDING OF EPILEPSY WITHIN HISTORICALLY BLACK SCHOOL

### IN THE WESTERN CAPE

Inkcukakca ngomthabathi nxaxeba

*Details of participants*

Igama: .....

Name:

Iminyaka mingaphi:.....

Age

Ibanga eliphezulo lwezifundo:.....

*Highest qualification*

1. Wazi ntoni ngesifo sokuwa okanye sokuxhuzula?  
*What do you know about epilepsy?*
2. Ulufumene phi olu lwazi unalo ngesifo sokuwa okanye sokuxhuzula ?  
*How did you obtain this knowledge about epilepsy?*
  - 2.1 Ezincwadini *Books?*
  - 2.2 Ngamava *Experience?*
  - 2.3 Kuqeqesho *Training?*
3. Kunjani ukukhulisa umntwana onesifo sokuwa/ukuxhuzula.  
*Tell us how is your experience in raising the child with epilepsy .*
4. Ingaba unalo ulwazi lukuba isifo sokuwa okanye sokuxhuzula singaba nento esiyenzayo ezifundweni zomntwana wakho  
*Are you aware of epilepsy is a barrier to learning?*
- 4.1 Ukuba uthi ewe cacisa ukwanzi njanu oko?  
*If yes explain how you know this?*
5. Ingaba lukho uncedo olufumanayo esikolweni malunga nomntwana wakho?  
*Is there any support you are getting from school regarding your child?*  
Nabisa  
*Explain*
6. Abafundisi ntsapho kwakunye nabanye abafundi bamthatha njani umntwana wakho nje ngomntu enesifo sokuwa okanye sokuxhuzulayo ?  
*How do educators and learners reacts towards your child at school?*
7. Abantu bokuhlala bamthatha njani umntwana wakho njengomntu onesifo sokuwa/sokuxhuzula?  
*How do people in your society react towards your child?*
8. Ingaba ikho enye into ocinga ingalucedo onokundixelela yona?  
*Is there anything else that you think would be useful for me to know?*

**APPENDIX C:**  
**INTERVIEW SCHEDULE FOR LEARNERS**



**UMGAQO WODLIWANO NDLEBE**  
**INTERVIEW SCHEDULES**  
**ABAFUNDI**  
**FOR LEARNERS**

**UKUQONDA NGESIFO SOKUWA /UKUXHUZULAKWIZIKOLO EZINEMBALI**  
**ZABAMNYAMAKWI PHONDO LWE NTSHOANA KOLONI**  
**UNDERSTANDING OF EPILEPSY WITHIN HISTORICALLY BLACK SCHOOL**  
**IN THE WESTERN CAPE**

Inkcukakca ngomthabathi nxaxeba

*Details of participants*

Igama: .....

Name:

Iminyaka mingaphi:.....

Age:

Ibanga okulo:.....

Grade:

1. Wazi ntoni ngesifo sokuwa okanye sokuxhuzula?  
*What do you know about epilepsy?*
2. Ulufumene phi olu lwazi unalo ngesifo sokuwa okanye sokuxhuzula ?  
*How did you obtain this knowledge about epilepsy?*
  - 2.1 Ezincwadini Books?
  - 2.2 Ngamava Experience?
  - 2.3 Kuqeqesho Training?
3. Ingaba unalo ulwazi lukuba isifo sokuwa okanye sokuxhuzula singaba nento esiyenzayo ezifundweni zomntwana zakho?  
*Are you aware of epilepsy is a barrier to learning?*
- 3.1 Ukuba uthi ewe cacisa ukwanzi njanu oko?  
*If yes explain how you know this?*
4. Ingaba lukho uncedo olufumanayo esikolweni malunga nesifo sokuwa?  
*Is there any support you are getting from school about epilepsy?*  
Nabisa  
*Explain*
5. Abafundisi ntsapho kwakunye nabanye abafundi bamthatha njani umntwana kuba unesifo sokuwa okanye sokuxhuzulayo ?  
*How do educators and learners reacts towards you at school?*
6. Abantu bokuhlala bakuthatha njani umntwanawakho njengomntu onesifo sokuwa/sokuxhuzula?  
*How do people in your own society react towards your ?*
7. Ingaba ikho enye into ocinga ingalucedo onokundixelela yona?  
*Is there anything else that you think would be useful for me to know?*

**APPENDIX D:**  
**THE TRANSLATED INTERVIEW:**  
**(PARTICIPANTS, EDUCATOR)**  
**EXAMPLE OF CODED TRANSCRIPTS**  
**FOR DATA ANALYSIS**

## EXAMPLE OF CODED TRANSCRIPTS FOR DATA ANALYSIS

| Interviewer   | Participants  | Generating Codes   | Categories/Themes              |
|---|---|--|--------------------------------|
| How are you mam?  | I am fine   |  |                                |
| What do you know about epilepsy   | <b><u>I know nothing about epilepsy.</u></b><br>I've only read that <b><u>people</u></b> fall when they get epilepsy and it is also referred to as the "amafufunyana".  | IAK<br>In accurate knowledge                             | Lack of Knowledge              |
| How is Reactions of Educators towards learners with epilepsy                                | The Staff at this school is very open and <b><u>loving</u></b> towards any child  | PS-Positive reactions                                    | Reactions                      |
| What effect does epilepsy has on learning   | Learners are normally <b><u>scared</u></b> & frightened when witnessing an <b><u>"attack"</u></b>   | F- frightened  | Effect of epilepsy on learning |
| How do classmates react towards the learner with epilepsy?                                  | learners are often teased about their condition, if a learner had an "attack" <b><u>they will joke about his condition</u></b>  | T. teasing   | Effect of epilepsy on learning |
| What factors are effecting educator's perception about inclusion of learners with epilepsy? | The educators need information and skill on how to handle learners with epilepsy. The school should have guidelines for learners with epilepsy.   | <b>SG</b> school guidelines<br><br><b>INC</b> –Inclusion | Effect of Epilepsy on learning |
| What support would you want for learners with epilepsy?                                     | Workshops and training  | <b>CC</b> – Curriculum change                            | Trained to be empowered        |
| Where do you think this support should/could come from?                                     | From the local clinic and the Department of Education ,the district   | <b>TES</b><br>Teacher education support                  | Inclusion in regular class     |
| How do people in the local community react towards learners with epilepsy?                  | The community and school do not know much about the child with epilepsy and this can be a big problem. This learners are often <b><u>labeled</u></b> by other members of community as (iqeqe') or regarded as mad. But I also think at this stage <b><u>people are conservative</u></b> and would handle a person with epilepsy much better | R – Rejection<br>A - Acceptance                          | Reaction of community          |

| Interviewer  | Participants  | Generating Codes   | Categories/Themes                    |
|--|---|--|--------------------------------------|
| What difficulties do you think might experience in the school and the community regarding the learner with epilepsy? | They use <u>traditional approach</u> the child with epilepsy would be regarded as an outcast in the community. At school we believe in <u>western medication</u> .  | <b>ROT</b><br>Role of traditions<br>MUE-Medication used for epilepsy | Reactions of educators and community |
| Is there anything else that you think would be useful for me to know?  | I've always thought of epilepsy as a curse or something being wrong with a person. In fact, <u>I sometimes thought of it as something coming from the devil</u> . Today I know that it is a disease like any other disease. The problem however is that I still do not really understand what it entails, but the department of education expects me to have this child in my class. I would love to learn more about epilepsy. | <b>ROT</b> – Role of tradition                                       | Beliefs                              |

### Emergent code

|   |   |  |
|---|---|--|
| <b>AK</b> – Accurate Knowledge<br><br><b>IAK</b> – In accurate Knowledge<br><br><b>PP</b> – Positive Perceptions<br><br><b>NP</b> – Negative Perceptions<br><br><b>PR</b> – Positive Reaction | <b>NG</b> Negative Reaction<br><b>F</b> – Frightened<br><b>T</b> – Teasing<br><b>INC</b> – Inclusion<br><b>SG</b> – School guidelines<br><b>B</b> - Beliefs | <b>CC</b> – Curriculum change<br><b>TES</b> – Teacher education support<br><b>ROT</b> – Role of traditions<br><b>R</b> – Rejection<br><b>A</b> – Acceptance<br><b>MUE</b> – Medication used for epilepsy |
|---|---|--|

**APPENDIX E:**  
**SUMMARY OF FIELD NOTES RELATED**  
**TO INTERVIEW SCHEDULE**

### Summary of Field Notes related to interview schedule

| PART 1 | INTERVIEW SCHEDULE  | COMMENTS   | CONNECTED TO THEMES                              |
|--------|---|--|--|
| E3     | What do you know about epilepsy?  | I don't know what is epilepsy maybe it's "amafufunyana"  | FN: In accurate responses                        |
| P4     |   | Epilepsy is an evil spirit (Umoya omdaka)  |  |
| L1     |   | Epilepsy is when I gets fits and I fall down   |  |
| P6     |   | My child was knocked by the car, and it's when he started to have fits.  |  |
| E2     | What effect does epilepsy has on learning?  | It disturb the class when I have to attend to the learner who had an "attack"                                  | FN: Reactions<br>Rejection                       |
| E16    |   | I don't know how to accommodate these learners in my class.  |  |
| E18    |   | Other learners get frustrated and they don't want to associate themselves with learners experiencing epilepsy. |  |
| P1     | Is your child using any medication for epilepsy? If yes<br>What medication does your child use? | My child is using Holy water and gets prayers from the Pastor.   | FN: Role of traditions<br>FN: Western medication |
| P2     |   | Epelium  |  |
| P3     |   | My child is using herbs from the herbalist.  |  |
| P4     |   | She receives treatment from the clinic, they gave her Bico and I also give her holy water from the church.     |  |

**Key: FN= Field Notes**

**APPENDIX F:**  
**CONSENT FORM FOR EDUCATORS,**  
**PARENT LEARNERS**

|  |
|--|
| <p style="text-align: center;"><b>ISIVUMELWANO SOKWENZA UPHANDO</b><br/> <b>CONSENT TO PARTICIPATE IN RESEARCH</b></p> |
|--|

**Ukuqonda nzulu ngesifo sokuwa (isimo sokuxhuzula) kwizikolo ezinembali zabamnyama kwi phondo lwe Ntshona Koloni.**

***Understanding of epilepsy within historically Black school in the Western Cape***

Uyacelwa ukuba athabathe inxaxheba kuphando lwemfundo olwenziwa ngumfundi ongu Yolanda Lupondo ofundela isidanga se Masitazi kwicandelo lwesebe lweze mfundo kwi Psychology eStellenbosch dyunivesiti. Iziphumo zolu phando ziyakuthi zincele ekubhalweni kwe Thesisi.Unobangela wokuba unyulwe kungexa yamava onawo/eninawo ngesifo sokuwa (isimo sokuxhuzula).

*You are asked to participate in a research study conducted by Yolanda Lupondo, an MEd student in the Department of Educational Psychology at Stellenbosch University. The results obtain from the research will be contribute to research thesis. You were selected as a possible participant in this study because of your experience about epilepsy.*

**1. INJONGO YOPHANDO**

***PURPOSE OF THE STUDY***

Ukuhlola indlela abantu abasiqonda ngayo isifo sokuwa (isimo sokuxhuzula) Kwizikolo ezinembali zabamnyama kwiphondo lwase Ntshona Koloni.

*To explore how epilepsy is understood within historically black schools in the Western Cape*

**2. INKQUBO**

***PROCEDURES***

Ukuba uyavuma ukuthabatha inxaxheba kolu phando lwesisifundo siyakukucela ukuba wenze ezi zinto zilandelayo:

*If you agree to participate in this study, would like you to do the following things.*

- 2.1 Ukuba uyavuma ukuthathabatha inxaxheba,ndicela ukukwenza udliwano ndlebe nawe. Olu dliwana ndlebe luyakuthi luthabathe imizuzu engamashumi amane anesihlanu ukuya kwi yure.Ingxoxo iyakuba phakathi komphandi nomphandwa bexoxa befuna ngokuqonda ngesifo sokuwa (ukuxhuzula) kwizikolo ezinembali zabamnyama kwiphondo lwe Ntshona Koloni.

*If you agree to participate in this study, I would ask you to be interviewed. The interview will take approximately one and half hours and will explore your understanding of epilepsy. The interview will be like a conversation with the researcher.*

- 2.2 Ngokwe sivumelwano umntu oyakuthi athabathe inxaxheba koluphando akayi Kuthi aziwe. Oku kukuthi igama lakhe aliyikupapashwa esidlangalaleni, ngaphandle kokuba umntu uyavuma ukuba igama lakhe lingapapashwa.  
*We agree that the interviewee will be protected through anonymity. This means that his/her name will not be revealed on any public documentation, unless she/he specifically indicates the wish for this to occur.*
- 2.3 Uphondo luyakuqhubeka kwizikolo ezichongiweyo ukwenza uphando olo.  
*Research will take place in selected schools.*



**3. IZINTO EZINOKUMFAKA ENGOZINI NOKUNGANWABI  
POTENTIAL RISKS AND DISCOMFORTS**

Akukho bungozi bulindelekileyo kolu nphando

*There are no risks in this research.*

**4. IZINTO EZINOKUXHAMLWA NGABATHATHI NXAXHEBA KWAKUNYE  
NOLUNTU**

**POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

Abathabathi nxaxeba koluphando bayakuthi bafumane ithuba lokwazi nzulu ngesifo sokuwa (ukuxhuzula). Ulwazi olo luyakuthi luncede izikolo ingakumbi abafundisi ntsapho, abafundi, abazali kwakunye noluntu jikelele.

*Participants will have an opportunity to learn more about epilepsy and the knowledge gained can benefit schools, especially the educators, learners, parents and society.*

**5. IHLAWULO KUBA THABATHI NXAXEBA  
PAYMENT FOR PARTICIPATION**

Akukho mali iyakuhlawulwa kubantu abathabatha inxaxeba koluphando.

*There will be no money paid out to the participants in this research.*

**6. UKUGCINA IMFIHLO NGOKUTHEMBEKILEYO  
CONFIDENTIALITY**

- 6.1 Naluphina ulwazi oluyakuthi lufumaneke koluphando malunga nawe luyakuba yimfihlelo, yaye luyakuchazwa esidlangalaleni ngokwemvume yakho okanye ngokwemvume yomthetho.

*Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.*

- 6.2 Abathabathi nxaxeba bayaku rhekhodishwa ngetheyiphu rekhoda , ngumphandi phambi kodliwano ndlebe nangelixa lodliwano ndlebe.

*We agree to the tape recording of the interview, unless specified by either the researcher/interviewer or interviewee before or during the interview.*

- 6.3 Uphando luyakuthi lubeyimfihlelo ngokuthi lugcinakale kumatshini wokucwethwasha (iLephutophu Computha) yomphandi.

*Confidentiality will be maintained and the information obtained will be stored on my personal laptop computer.*

- 6.4 Xa kunatyiswa izimvo zaba thabathi nxaxeba, izimvo zabo ziyakuphawula ngokuthi umfundi uthi, umzali uthi. umfundisi ntsapho uthi.

*When doing the analysis participants will be coded according to learners, parents and educators.*

- 6.5 Iziphumo ziyakuthi zifumaneke kwisebe lwezemfundo eNtshona Koloni, kwizikolo ezithe zathabatha inxaxheba, abavavanyi abangaphandle nangaphakathi, kumongameli wophando, nabantu abathe bathabatha inxaxheba kuphando.

*The results will be made available to the Western Cape Department of Education, the participating schools, external examiners, internal examiners, supervisors and participants.*

- 6.6 Injongo zokupapasha iziphumo kukuvula ingqondo zabantu bazi nzulu ukuba ingaba abantu abanesifo sokuwa sibachaphazela njani na? Yintoni enokwenziwa zizikolo ukuhlangabezana nabafundi abanesifo sokuwa (ukuxhuzula).

*The purpose of publishing results will be to help to create awareness and depth understanding of how people are affected by epilepsy and what schools can do in order to accommodate learners with epilepsy.*

**7. UKUTHABATHAINXAXEBA NOKURHOXA**

***PARTICIPATION AND WITHDRAWAL***

Siyaqonda ukuba umntu othabatha inxaxheba koluphando unelungelo lokurhoxa xa efuna, nangaliphi na xesha, ngaphandle koloyiko lokohlwaywa. Zonke izinto ezirhekhodishiweyo ngaye umntu zaku rhoxiswa kuphando olo. Siyayiqonda ukuba unthabathi nxaxheba akabophelelekanga ukuba aphenhule yonke imibuzo ebuzwayo.

*We understand that the interviewee has the right to withdraw from the study at any time without fear of penalty, including having his or records withdrawn from the study. We also understand that the interviewee may choose at any time not to answer a particular question.*

**8. UCHONGO LWABAPHANDI**

***IDENTIFICATION OF INVESTIGATORS***

Ukuba unebuzo malunga noluphando unakho ukuthinta ngokukhululekileyo aba bantu balandelayo.

*If you have any questions or concerns about the research, please feel free to contact the researcher or the supervisor*

1. Umphandi/Researcher: Yolanda Lupondo  
ABRAHAMKATZ ROAD  
MONTANA  
7490  
(021 633 2958)  
(021 934 9404)  
(083 741 8661)  
Yolanda22@telkomsa.net
2. Umongameli wophando / Supervisor: Lynette Colliar  
DEPARTMENT OF EDUCATIONAL  
PSYCHOLOGY, UNIVERSITY OF  
STELLENBOSCH  
(021 8082304)  
[lyncol@sun.ac.za](mailto:lyncol@sun.ac.za)

**9. AMALUNGELO ABATHABATHI NXAXEBA  
RIGHTS OF RESEARCH SUBJECTS**

Unakho ukurhoxa kwesi sivumelwano nangaliphina ixesha ngaphandle koloyiko lwesohlwayo. Ukuba unemibuzo malunga namalungelo akho njengo mthabathi nxaxheba kolu phando nceda uqhagamshelane neziko lophuhliso lwezophando. Inombolo: 021 8082304

*You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research subject, contact the Unit for Research Development.*

*Number: 021 8082304*

**APPENDIX G:**  
**LETTERS OF PERMISSION**



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvenoot • your knowledge partner

11 September 2009

Tel.: 021 - 808-2687  
Enquiries: Sidney Engelbrecht  
Email: sidney@sun.ac.za

Reference No. 210/2009

Ms Y Lupondo  
Department of Educational Psychology  
University of Stellenbosch  
**STELLENBOSCH**  
7602

Ms Y Lupondo

#### APPLICATION FOR ETHICAL CLEARANCE

With regards to your application, I would like to inform you that the project, *Understanding op epilepsy within a historically Black school in the Western Cape*, has been approved on condition that:

1. The researcher/s remain within the procedures and protocols indicated in the proposal;
2. The researcher/s stay within the boundaries of applicable national legislation, institutional guidelines, and applicable standards of scientific rigor that are followed within this field of study and that
3. Any substantive changes to this research project should be brought to the attention of the Ethics Committee with a view to obtain ethical clearance for it.
4. The researcher will implement the foregoing suggestions to lower the ethical risk associated with the research.

We wish you success with your research activities.

Best regards



**MRS. MALÈNE FOUCHÉ**  
Manager: Research Support

Afdeling Navorsingsontwikkeling • Division of Research Development

Privaat Sak/Private Bag X1 • 7602 Stellenbosch • Suid-Afrika/South Africa

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Reference  
ISalathiso

Dr RS Cornelissen

(021) 467-2286

(021) 425-7445

20090630-0047



Wes-Kaap Onderwysdepartement

Western Cape Education Department

ISebe leMfundo leNtshona Koloni

Mrs Yolanda Lupondo  
9 Abrahamkatz Road  
MONTANA  
7490

Dear Mrs Y. Lupondo

**RESEARCH PROPOSAL: UNDERSTANDING OF EPILEPSY WITHIN HISTORICALLY BLACK SCHOOL IN THE WESTERN CAPE.**

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **20<sup>th</sup> July 2009 to 20<sup>th</sup> August 2009**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr R. Cornelissen at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the following schools: **Siviwe School of Skill, Nomsa Mapongwana Primary, Luleka Primary and Isikhokelo Primary.**
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

**The Director: Research Services  
Western Cape Education Department  
Private Bag X9114  
CAPE TOWN  
8000**

We wish you success in your research.

Kind regards.

Signed: Ronald S. Cornelissen  
for: **HEAD: EDUCATION**  
**DATE: 30<sup>th</sup> June 2009**

MELD ASSEBLIEF VERWYSINGSNOMMERS IN ALLE KORRESPONDENSIE / PLEASE QUOTE REFERENCE NUMBERS IN ALL CORRESPONDENCE /  
NCEDA UBHALE INOMBOLO ZESALATHISO KUYO YONKE IMBALELWANO

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